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The San Francisco AIDS Oral History Series

THE AIDS EPIDEMIC IN SAN FRANCISCO: THE RESPONSE OF THE NURSING PROFESSION, 1981-1984

Volume III

Diane Jones, R.N.

FIRST WAVE OF THE NURSING STAFF ON THE AIDS WARD, SAN FRANCISCO GENERAL HOSPITAL

Clifford L. Morrison, M.S., M.N., R.N., ORGANIZER OF THE AIDS WARD, SAN F.A.A.N.

FRANCISCO GENERAL HOSPITAL

With an Introduction by Helen M. Miramontes, R.N., M.S., F.A.A.N.

> Interviews Conducted by Sally Smith Hughes, Ph.D. in 1995 and 1996

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THE AIDS EPIDEMIC IN SAN FRANCISCO: THE RESPONSE OF THE NURSING PROFESSION, 1981-1984, Volume III, 1999, xv, 275 pp.

Diane Jones, (b. 1952) head nurse of Ward 5B at San Francisco General Hospital (SFGH): discusses hospital staff discrimination against AIDS patients; establishes Ward 5B at SFGH as an AIDS inpatient ward; Shanti, Ward 86 and other AIDS services at SFGH; Ward 5B as a nurse-run unit, and locus for early AIDS activism and advocacy. <u>Clifford L. (Cliff)</u> <u>Morrison</u>, clinical nurse specialist and founder of the AIDS ward (Ward 5B) at SFGH; education and upbringing in rural Florida; background in AIDS work; establishes Ward 5B, an AIDS inpatient ward; the workings of Ward 5B; comments on early AIDS physicians, Merle Sande and Mervyn Silverman; media impact on Ward 5B and the AIDS crisis; development of AIDS infection control procedures; Shanti, Hospice and other counseling services; AIDS nursing and the epidemic's impact on the profession; the San Francisco Model of AIDS care and Ward 5B.

Introduction by Helen M. Miramontes, R.N., M.S., F.A.A.N., Associate Clinical Professor, Community Health Systems Department, School of Nursing, University of California, San Francisco.

Interviewed 1995-1996 by Sally Smith Hughes, Ph.D., for the San Francisco AIDS Oral History Series. Regional Oral History Office, The Bancroft Library, University of California, Berkeley.



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SERIES INTRODUCTION--Helen M. Miramontes, R.N., M.S., F.A.A.N.

Nursing and medicine were confronted with very similar challenges in 1981 when HIV infection surfaced as a new unidentified disease in the gay communities of San Francisco, Los Angeles, and New York City. At that time it was not know whether this new phenomenon, named Gay-Related Immune Deficiency (GRID), was infectious and contagious, and if so, how it was transmitted. Were nurses, like physicians, at risk for becoming infected if they provided care, and would their families also be at risk for contracting this disease? There was much speculation and controversy as to the potential etiology of the new disease. Some people including members of the impacted gay community, proposed that this new disease was the result of recreational drug use, such as "poppers" (nitrates) and indiscriminate anonymous sexual activity, as demonstrated by the popularity of bathhouses in the gay community, and not due to an infectious organism. A few very knowledgeable physicians/ disease specialists, such as Don Francis, hypothesized that this new disease was caused by an infectious agent, probably a virus, and transmitted by means similar to hepatitis B. There was a lot of fear among health care providers about contagion, but there was also significant prejudice and discriminatory behavior because the new disease was identified in a population (gay/bisexual men) that was stigmatized by the larger society. Identification of the disease in people of color, especially African Americans and injection drug users, only exacerbated the biases, prejudices, and discriminatory behavior.

Many nurses demonstrated the same attitudes, beliefs, and behaviors seen in the larger society. I was a critical care nurse working in an intensive care unit (ICU) in a large teaching facility of a health maintenace organization in Santa Clara county. In the early years of the epidemic, it was not unusual to have two to three patients with *Pneumocystis carinii* pneumonia on ventilators in the ICU at any one time. Because some nurses avoided taking care of these patients, several of us volunteered to care for them on a regular basis. Inappropriate infection control techniques by health care providers, such as wearing gowns, masks and gloves for simple, nontransmissable activities, were the norm rather than the rarity. There were frequent breaches in confidentiality, not only among nurses but also among other health care workers. Similar situations occurred in San Francisco facilities as well.

Fortunately, some nurses rose above their fears and volunteered on a regular basis to provide the care and support required to meet the needs of these very ill and frequently terminal patients. Nurses also participated in community activities and organizations that were established to respond to this new disease. They creatively utilized the skills and expertise developed in caring for patients/clients in traditional settings, such as hospitals, clinics, and homes, to establish programs in community-based organizations. I saw nurses training volunteers to provide practical and emotional support, educating their peers and the public about the disease, advocating for compassion and resources, working with families impacted by this disease, and participating in policy development and political action that was vital to enhancing community response to this growing epidemic. Some of these nurses were also members of the at-risk community; others had family or friends as members of the gay community, and others became involved as a response to the hysteria and fears within the health care environment. But all demonstrated core values of nursing compassion and care.

Individual nurses, such as Cliff Morrison, Helen Schietinger, Gary Carr, and others, did not hesitate to become proactive, not only in care, but also in advocacy. These nurses did not wait for the nursing organizations to initiate a response to the epidemic. In fact, it was individual nurses who pressured and guided the nursing associations to develop position statements, to provide testimony before legislative bodies, and to mount positive responses concerning the epidemic, educating nurses as well as the public. Traditional nursing organizations, like traditional medical organizations, were not only hesitant, but resistant to becoming aggressively involved in the epidemic. It was a few nurses within the California Nurses Association who provided much of the expertise in education and training that formed the foundation of a very successful statewide education and training program for providers funded by the state for ten years. And it was these nurses who also lobbied for funds and provided expert testimony on numerous pieces of state legislation. These California nurses also provided leadership at the national level with the American Nurses Association on federal legislation. Some of these nurses provided leadership in clinical settings as well.

It was Cliff Morrison, as a clinical nurse specialist at San Francisco General Hospital, who designed and implemented a special unit for people with AIDS (Pas). This special unit, with integrated treatment, care, and support services, became the "gold standard" for inpatient care and was duplicated across the country. Later Cliff became the deputy director of a large Johnson & Johnson Foundation grant that successfully implemented HIV/AIDS care systems, similar to the San Francisco model, in eleven cities across the country.

Nurses also implemented other services in San Francisco communitybased organizations. One of the nurses, Helen Schietinger, established the housing program of the Shanti Project. These early models of nurses responded creatively and effectively to the needs of the statewide nurse case manager for home care developed in the mid-1980s by a nurse, Peggy Falkner, in the State Health Department Office of AIDS. The Ward 86, San Francisco General Hospital, Outpatient Clinic is world renowned for the quality of care and the expertise of its staff, many of whom are nurse practitioners like Gary Carr. UCSF AIDS Clinic also has highly qualified nurse practitioners. Nurses were and are also significantly involved in AIDS Drugs Clinical Trials, including the San Francisco Community Consortium headed by Donald Abrams, M.D.

Nurses have always been involved with the poor and most vulnerable of a society's citizens. Each war, epidemic, and community disaster has had nurses in the middle of the crisis, providing a variety of services, care, and support. The AIDS epidemic is no different. In fact, in the early years before there was effective treatment, the caring of nurses was too often all that we could give. Often these nurses are not identified in the media or the history books; they are the "unsung heros." But it is often the nurse who sits with the patient and/or the family through the many critical episodes of AIDS; who counsels a person just receiving the positive results of an HIV test; who holds the hand of a dying person at night; who embraces a mother crying over the death of a son or daughter.

Some of us believe that everything in our professional lives, and sometimes our personal lives, has led us to this pandemic. The work has become a mission and we are committed to the long haul. Unfortunately, as of March, 1999, there appears to be no end in sight. The worldwide pandemic continues to rage out of control with 90 percent or more of new infections occurring in developing countries in Africa and Asia at the rate of 16,000 new infections per day. In some countries in the southern regions of Africa, 20 to 30 percent of the general populations are already infected. In this country, annual new infections have remained unchanged for several years and therapeutic drug treatments are not accessible to everyone who is infected. The need for nurses and nursing care continues to be vital and critical to our overall social response. Nurses will continue to participate and to use those nursing values and skills that best meet the need of people infected and affected by HIV/AIDS.

> Helen Miramontes, R.N., M.S., F.A.A.N. Associate Clinical Professor Community Health Systems Department School of Nursing, UCSF

March 1999 San Francisco, California



SERIES HISTORY--by Sally Smith Hughes

Project Origin

The idea for an oral history series on the medical impact of the San Francisco AIDS epidemic originated with Evelyne and David Lennette, virologists who have been following the history of the disease since its first recognition in 1981. In 1991, they began generously to provide support for interviews with physicians at the University of California, San Francisco [UCSF] and San Francisco General Hospital [SFGH] who were prominent in AIDS medicine in its earliest phase, 1981-1984. That series with twelve physicians, two dentists, and one epidemiologist--the AIDS physicians series--is now complete and available for research at the Bancroft and UCSF libraries.

The physicians' accounts made evident the critical role of nurses in AIDS history. It seemed imperative to capture their story. In 1994 we applied for and received a two-year award of \$60,000 from the University of California Universitywide AIDS Research Program to interview ten nurses active in AIDS nursing in San Francisco. We gratefully acknowledge UARP's support of phase 2--the AIDS nurses series--of the AIDS oral history project. Jointly sponsored by the Regional Oral History Office of the Bancroft Library, UCB, and the Division of the History of Health Sciences, UCSF, it significantly expands oral documentation of the AIDS epidemic. As in the earlier series, the focus is on the first three years of the epidemic when San Francisco led the way in many areas of AIDS nursing and medicine.

Primary and Secondary Sources

To prepare for the interviews, I used the documents and publications described in the "Series History" essay appearing with the AIDS physicians series oral histories. In addition, interviewees in the nurses series in several cases provided documents from their personal files which added immeasurably to the oral account. I wish particularly to thank Angie Lewis, Grace Lusby, Michael Helquist, and Helen Schietinger for the time they took to select, compile, and donate documents for the historical record. These documents will be deposited in the AIDS History Project Archives at UCSF Library.

The Oral History Process

The oral history methodology used in this project is that of the Regional Oral History Office, founded in 1954 and producer of over 1,400 archival oral histories. The method consists of background research in primary and secondary sources; systematic recorded interviews; transcription, editing by the interviewer, and review and approval by the interviewee; deposition in manuscript libraries of bound volumes of transcripts with table of contents, introduction, interview history, and index; cataloging in national on-line library networks (MELVYL, RLIN, and OCLC); and publicity through ROHO news releases and announcements in scientific, medical, and historical journals and newsletters and via the UCSF Library web page (http://www.library.ucsf.edu/). The reader interested in the pros and cons of the oral history method is referred to the "Series History" in the AIDS physicians volumes.

Oral histories in the AIDS nurses series ranged in length from two to ten hours. Details of the interview process with specific individuals may be found in the interview history preceding each oral history transcript. The oral history volumes, tapes, and supporting documents will be available for research in the AIDS History Project Archives at UCSF Library.

Emerging Themes

ROHO'S AIDS series consists to date of twenty-five oral histories on the medical and nursing response to the San Francisco AIDS epidemic in its first three years. There is a wealth of information on its medical, scientific, political, social, and personal aspects. Although it is impossible to do justice to this collection in a brief summary, the following comments suggest in broad outline the richness of the thematic material.

These oral histories with nurses continue the themes running through the physicians series--individual "preparedness" for the epidemic in both professional and personal senses; organizing medical, nursing, and social services in the face of a new and fatal disease; the epidemic's impact on the careers and emotional life of health care providers. Compared to the oral histories with physicians in phase 1, what is generally different about the oral histories with nurses is their portrayal of a day-to-day, hands-on, in-the-trenches engagement with the people most affected by the epidemic--the people with AIDS. Some of this distinction is due to the different requirements of the two professions. Put simplistically, physicians diagnose, treat, and prescribe for patients on an episodic basis. Their contact with patients, particularly in an incurable disease such as AIDS, may run for years, even decades, but is broken up into episodic bedside, clinic, or office visits.

Such is not the case with hospital nursing. As long as the patient is hospitalized, a nurse or nurses is caring for the patient in an immediate, personal, and ongoing fashion. The highs and lows of the nurse-patient relationship are difficult to escape, as these oral histories indicate. Because nursing contact with patients tends to be more sustained and personal than is physicians', it is often more of a struggle to sustain a proper balance between personal involvement and professional detachment. Some of the nurses in these volumes speak of "burnout" as a consequence of over-commitment and of the measures they take to lessen or escape it.

The role of the gay community in AIDS activities is another persistent theme. The fact that six of the ten interviewees in this series are gay or lesbian is not incidental. In most cases, their sexual orientation was a basis for their original engagement in the epidemic, which to this day in San Francisco affects gay men in larger numbers than any other single demographic group. AIDS in the years covered by this project was widely perceived as a "gay" disease. The nurses in this series had the same perception and in many cases chose AIDS care as a way of assisting members of "the community", meaning the articulate and organized gay and lesbian community centered around, but not limited to, Castro Street in San Francisco. Thus it is inevitable, as these oral histories vividly demonstrate, that the history of AIDS in San Francisco, is inextricably intertwined with gay culture.

Yet another important theme is the impact of the epidemic on the stature of nursing. Although AIDS in San Francisco has always been a multidisciplinary activity, involving health care professionals, social and community workers, government agencies, etcetera, the interviews show nurses taking on more responsibilities, devising innovative services for holistic AIDS care, and assuming a stronger "voice" in the medical hierarchy. For example, it was nurses who organized and ran (of course with physician oversight), and continue currently to run the inpatient AIDS unit, Ward 5B (now 5A), at San Francisco General Hospital. Nurses also played a major role in structuring comprehensive patient management and community support systems which are a critical part of the multidisciplinary model of AIDS care for which San Francisco was known in the early epidemic. I hope the reader will be prompted to read on and to take from these oral histories much more than I have suggested here.

Locations of the Oral Histories

The oral history tapes and bound volumes are on deposit at UCSF Library's AIDS History Project Archives. The volumes are also available at the National Library of Medicine, the Bancroft Library, UCLA, and other manuscript libraries.

Acknowledgements

We are grateful to Helen Miramontes, Associate Clinical Professor in the Community Health Systems Department at UCSF School of Nursing, for writing the introduction to the AIDS nurses oral history series. Ms. Miramontes has been involved with AIDS activities at the federal state, and local levels. At UCSF, she served as Deputy Director of the International Center for HIV/AIDS Research & Clinical Training in Nursing. In 1996, she was named to the Presidential Advisory Council on HIV/AIDS.

We also wish to thank editorial assistants Grace Robinson, Julia Rechter, and Celeste Newbrough, and production manager Shannon Page for their efforts in finalizing the oral history volumes. I am grateful as always to Willa Baum, Regional Oral History Office director, for her oversight and helpful comments.

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Note Regarding Terminology

In this project, both interviewer and interviewee sometimes use the term "AIDS" to refer to the disease before it had been officially given this name in the summer of 1982. "AIDS" is also used to designate the disease which in recent years has come to be known in scientific and medical circles as "HIV disease". In these oral histories, the term "AIDS" has been retained, even when its use is not historically accurate or in tune with contemporary technical terminology.

> Sally Smith Hughes, Ph.D. Research Historian and Project Director

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- Mervyn F. Silverman, M.D., M.P.H., "Public Health Director: The Bathhouse Crisis, 1983-1984"

VOLUME II

- Donald I. Abrams, M.D., "The KS Clinic, Lymphadenopathy and AIDS-Related Complex, and the County Community Consortium"
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- Donald P. Francis, M.D., D.Sc., "Epidemiologist, Centers for Disease Control: Defining AIDS and Isolating the Human Immunodeficiency Virus (HIV)
- Merle A. Sande, M.D., "Infectious Disease Specialist: AIDS Treatment and Infection Control at San Francisco General Hospital"
- John L. Ziegler, M.D., Ph.D., "Oncologist: Kaposi's Sarcoma and AIDS Research in San Francisco and Globally"

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IN PROCESS

Jay A. Levy, M.D., Virologist, UCSF: Isolation of the AIDS Virus Warren Winkelstein, Jr., M.D., M.P.H., The San Francisco Men's Health Study, UC Berkeley PHASE 2: THE RESPONSE OF THE NURSING PROFESSION, 1981-1984

VOLUME I

- Michael J. Helquist, "Journalist of the Early AIDS Epidemic in San Francisco"
- Jeannee Parker Martin, R.N., M.P.H., "The AIDS Home Care Program of Visiting Nurses & Hospice of San Francisco"
- Helen K. Schietinger, R.N., M.F.C.C., "Nurse Coordinator of UCSF's First AIDS Clinic"

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The San Francisco AIDS Oral History Series

THE SAN FRANCISCO AIDS EPIDEMIC: THE RESPONSE OF THE NURSING PROFESSION, 1981-1984 VOLUME III

Diane Jones, R.N.

FIRST WAVE OF THE NURSING STAFF ON THE AIDS WARD, SAN FRANCISCO GENERAL HOSPITAL

An Interview Conducted by Sally Smith Hughes, Ph.D in 1995 and 1996

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Ward 5B (SFGH) original nursing staff, December, c. 1990.

Left to right: Lori Green, Cliff Morrison, George Jalbert, Bill Nelson, Ann Steinlauf, Alyssa Chandler, Charles Cloniger, Steve Keith, Alison Moed, Bill Barrick, Diane Jones, and center: Bob Adrian. Not shown: Cathy Juristo.

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INTERVIEW HISTORY--Diane Jones

Diane Jones was a founding member and staff nurse of the AIDS Special Care Unit, the celebrated in-patient AIDS ward 5B, at San Francisco General Hospital. In 1990, she became Head Nurse of the unit, retiring in 1996. Although broken by a year of service on a pediatric unit (1989-1990), her long years of providing nursing care for desperately ill patients hospitalized with HIV disease/AIDS is the basis for this oral history.

The oral history captures the culture and day-to-day operations of 5B in the years following its formation in 1983. The story as Jones tells it is a complex blend of practical nursing and medical needs, social support for both patients and staff, and tensions within the unit and between the units, and the starkly different culture of the hospital as a whole. Not only were the early patients and staff largely gay, but the disease was widely feared and the patients stigmatized. It is nursing that is at the core of her account, AIDS nursing in specific, and one has the feeling that Jones represents nursing at its best. Articulate and perceptive, she provides a real-life description of the problems, complexities, and rewards of working in the early days of the epidemic on a nursing unit created specifically to care for patients with AIDS. One learns her philosophy towards holistic treatment of patients: psychosocial needs were as much a part of ward regimen as nursing and medical care. She also was careful to take care of herself. While 100 percent dedicated to Ward 5B while she was working, she also had a daughter to mother and outside political commitments. The two worlds, she found, informed each other. The oral history concludes with her view of how the AIDS epidemic has impacted nursing in general. Typically, she singled out AIDS patients with their new-found advocacy and demand for allies in nursing as a major force behind progress in the nursing practice.

The Oral History Process

Two interviews were conducted on October 17 and December 29, 1995 in Jones's apartment which she shares with her teenage daughter Annie in San Francisco's Mission District. Jones' manner was thoughtful and serious, tempered perhaps by tiredness after a full day as Head Nurse on the AIDS unit. She returned the edited transcripts with minimal editorial changes.

This is the oral history of an articulate and discriminating woman who has experienced the epidemic up front and close. The following remarks suggest the basis for her continuing commitment, presently as Head Nurse on San Francisco General's AIDS Special Care Unit: All along, the thing that's drawn me the most is the political dimensions of the epidemic and the personal dimensions, all of the questions that it raises about life and death and sexuality and discrimination and drugs and addiction and family dynamics and pain and despair and hope and courage, all of those things that patients and their families and their loved ones go through.

> Sally Smith Hughes, Ph.D. Research Historian and Project Director

June 1999 Regional Oral History Office The Bancroft Library University of California, Berkeley Regional Oral history Office Room 486 The Bancroft Library University of California Berkeley, California 94720

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community organizing, HIVE druguisers
Other interests or activities
Organizations in which you are active Harm Reduction (calific)
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I FAMILY BACKGROUND, EDUCATION, AND EARLY CAREER

[Interview 1: October 17, 1995, Jones's flat in San Francisco] ##1

Family Background and Education

- Hughes: Would you start with where you were born and educated?
- Jones: I was born and raised in France--which is why my name is pronounced "Dee-on" and not "Die-ann"--right outside of Paris. I was born of American parents who were living in Europe since 1946. My father worked for a multinational corporation, International Harvester. I was born in 1952 and lived in Europe until 1970, through my first year of university, and was educated in French. I went through high school in Belgian schools.
- Hughes: Because your family moved to Belgium?
- Jones: Right, in 1963. My first year of college [American College in Paris], I spent back in Paris, and then finished university in the United States, right outside of Boston, at Tufts University. I spent two years there, from 1970 to 1972, and got a bachelor's degree in history and political science. So those were my first two years of living in the United States.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

1

Early Career

Peace Corps, 1972-1974

Jones: When I finished college in 1972, I joined the Peace Corps (1972-1974), and I went to live in French-speaking West Africa, in a small country called Togo, which is right next to Ghana. I lived in a remote area in northern Togo, right near the Ghana border, and worked in the field of health education, both in elementary schools and also in the health care system. I set up prenatal and well-baby clinics in village dispensaries and organized different public health-related projects--wells, latrine systems, building small maternities, et cetera.

San Francisco Women's Centers, 1975-1982

Jones: I lived there until 1975, and then came back to the United States and moved here to San Francisco. I worked primarily for the next few years [1975-1982] in and around San Francisco Women's Centers, which is a women's organization which sees their job as helping initiate and support different projects around women's issues. People from San Francisco Women's Centers were involved in starting La Casa de las Madres, the first home for battered women, and the Women's Alcoholism Center. We organized a huge women and violence conference in 1976 that was attended by 1,300 women and did a lot of political organizing. And then in 1979, we purchased a building on 18th Street and created the Women's Building. So during those times, I was either on the staff of San Francisco Women's Centers or on its various sponsored projects.

Around 1979, I decided to go back to school to get a nursing degree [1982] and went to City College [of San Francisco].

- Hughes: Why did you decide on nursing?
- Jones: Because I was interested in health care. I had enjoyed the work that I had done in west Africa, and by then, I had a child. My daughter was born in 1979. So I was interested in working in health care, and I was also interested in working part-time so that I could continue doing political organizing work. There were a multitude of jobs available for nurses at that time. So I went to City College and got a nursing degree and graduated in 1982.

II THE AIDS EPIDEMIC

Encountering AIDS Patients on the General Medicine Unit at San Francisco General Hospital

- Jones: I went to work at San Francisco General Hospital [SFGH], and was assigned to a general medicine floor, where the few AIDS patients that we were starting to see were being admitted, since it was considered part of internal medicine.
- Hughes: What month did you start?
- Jones: In September, 1982.
- Hughes: So the epidemic had been recognized for a little over a year.
- Jones: Yes. We had on the average one or two patients.
- Hughes: And what were they manifesting?
- Jones: PCP [Pneumocystis carinii pneumonia], for the most part. At the time, there was still a very high mortality rate associated with Pneumocystis. Almost 30 to 40 percent of the patients admitted to the hospital with Pneumocystis were dying. So it was usually pretty severe Pneumocystis. But there were other opportunistic infections, cryptococcal meningitis, a lot of the diarrheas, toxoplasmosis, complications from Kaposi's sarcoma. Primarily gay men, and a pretty broad socioeconomic mix, broader than the rest of the population of San Francisco General, which is primarily poor and indigent.
- Hughes: Why?
- Jones: Well, because I think the private sector was deliberately not wanting to treat them.

By January of 1983, the University of California Medical Center made the decision to open the AIDS Clinic at San Francisco General. There had been a fledgling clinic [Kaposi's Sarcoma Clinic] up on the hill, on Parnassus.¹ The decision was made in conjunction with the Department of Public Health to move the clinic to San Francisco General and combine it with the clinic that Paul Volberding and Connie Wofsy were running, both the oncology clinic that Paul was running where they were seeing a lot of the Kaposi's sarcoma patients, and then Connie was seeing patients in infectious disease clinics. Then Donald Abrams had his patients at Moffitt Hospital at UCSF.

- Hughes: Now, did you see that as a straightforward, noncontroversial event?
- Jones: I was actually oblivious of it. I mean, I knew that the clinic came into being, but I was oblivious to the politics of it, because they really were UC politics, and UC-Department of Public Health politics, at a much higher level. I was a city and county employee, so I didn't know.² I was working night shifts.
- Hughes: Yes, it didn't mean anything to you.
- Jones: It didn't mean anything to me. All I saw were the patients and how badly they were being treated. It was at a much more personal level.
- Hughes: Were you seeing all the different manifestations as one syndrome, as early as September 1982?
- Jones: Yes. We knew AIDS pretty much as we know it now. The latter manifestations of HIV disease, like CMV [cytomegalovirus] retinitis, were not as common. A lot of it was PCP. People were dying of PCP so quickly that they weren't surviving long enough to develop these latter stages, MAC [Mycobacterium avium complex] and the CMV infections. So that first year, I think the most obvious thing was the Pneumocystis. And I think on the average, the numbers of patients were increasing.

¹ For more on the Kaposi's Sarcoma Clinic, see the oral histories with Marcus A. Conant in the San Francisco Bay Area AIDS Oral History Project, phase 1: AIDS physicians, and with Helen Schietinger, in phase 2: AIDS nurses.

² San Francisco General Hospital is a City and County of San Francisco Department of Public Health hospital, administered under a contract with UCSF.

The Nursing Team on the General Medicine Unit

- After a three-month orientation on the day shift, I went to the Jones: night shift, just because that's the tradition in terms of seniority. At the time, because seniority was determining which shift you ended up on, there was always then a very high concentration of novice nurses who were running the night shifts of all these units. It turned out that there were four R.N.'s. three of us being new graduates and one being just two years out of nursing school. She was twenty-two years old. We were supposed to be providing the leadership for this very large unit; it was a thirty-four-bed unit. And the other members of the team were a L.V.N. [Licensed Vocational Nurse] and two nursing assistants who had been there for eighteen to twenty years and basically took on once again the task of training us and orienting us. We were making twice the amount of money that they were making.
- Hughes: Now, you were dealing with the full gamut of patients on the medical unit?
- Jones: Right.
- Hughes: Is it true that because it was a medical unit, you would be more likely to see PCP and that KS would have been referred elsewhere?
- Jones: No, KS would have been a medicine admission. The only patients that we didn't generally see were patients whose main reason for being admitted to the hospital was surgical procedures; they would have been on another floor.
- Hughes: Volberding talked about seeing a KS patient on the first day that he became director of the Division of Oncology. How did a KS patient get to the oncology clinic? Are you using "medicine" in a broad way--
- Jones: Well, no. Clinics are set up differently than inpatient units. Oncology is a subspecialty of internal medicine. So just like under surgery you have trauma and elective surgery and microsurgery or whatever, so KS patients might be seen at the oncology clinic. But when they have to come into the hospital, they're going to come to a medical unit. If the patients didn't require surgery, they were on our floor. If they required surgery, they went to a surgical floor.

Hospital Discrimination Against AIDS Patients

- Hughes: You said a moment ago that AIDS patients were badly treated. Tell me a bit more about that.
- Jones: Well, I think there was a considerable amount of fear that was intertwined with a lot of homophobia. It was really hard to separate out where the AIDS phobia and the homophobia started and ended. You know, we didn't know what caused this disease; we weren't sure about how it was transmitted; we didn't know how contagious it was. Certainly I think the larger question of, Could this be airborne, contributed to a lot of anxiety.

The policy was to put people in single hospital rooms. There were inconsistent messages in terms of what precautions needed to be taken, so you had the whole gamut: people taking no infection precautions, and other people doing the space suit module before going into a patient's room.

But I think the main form of poor treatment was neglect. People were avoiding having to interact with the patients as much as possible. There would be occasionally some more overt comments that would get made, or people being really blaming in their approach to patients. When physicians, for example, took a detailed medical history of the patient and delved into people's sexual practices and documented them fully through the charts--the multiplicity of sexual partners, et cetera--that kind of created this sort of voyeurism.

- Hughes: Did that worry you? Well, the voyeurism I presume would, but I'm thinking more of confidentiality issues.
- Jones: Well, not only in relationship to AIDS. Patients' confidentialities are being violated every day in large hospitals and teaching institutions. So it wasn't so much the question of confidentiality that was the issue; it was the discrimination and the homophobia that really were disturbing.
- Hughes: Was the sexual history that was taken different from what would have been taken for a non-AIDS patient?
- Jones: Well, I think that the thing that's hard to separate is that AIDS is a sexually transmitted disease, so it is appropriate to take a detailed sexual history. What people were becoming cognizant of was that health care professionals were interacting with a patient population that, were it not for AIDS, these young men would not necessarily ever need to be hospitalized, unless they were in a car wreck on Highway 101 and brought in through the trauma center.

That whole aspect of gay male sexuality of the early 1980s, and the large number of anonymous sexual partners, and the bath scenes, and the whatever, was something that was completely foreign and new that people had never encountered. And also, we were trying to learn how the disease was transmitted. It was known that it was likely to be a sexually transmitted disease. So there was a part of that history taking that was appropriate, and another part of it, though, that had this element of voyeurism. Part of it was because some of the stories were so astounding, because of the large numbers of sexual partners some men were saying that they'd had, and the high degree of anonymous sex, which was outside the "norm."

I don't remember witnessing a lot of gross violations of confidentiality in terms of disclosure of diagnosis, because I think pretty early on, the standards were established. There was contention around what the standards should be around disclosure of diagnosis. The question of disclosure fit within the context of confidentiality laws within medicine, so you had no more the right to tell a visitor that your patient had diabetes than you did that they had AIDS.

- Hughes: Right. But the consequences could be greater if you revealed that a patient had AIDS.
- Jones: Right. But I don't see that as having been a very sharp issue. That's not how the homophobia came down. To me, the homophobia came down in profound neglect, disrespect, not being able to incorporate people's alternative family structures into what traditional hospital policies are. But mainly, a lot of neglect and repulsion. And it was also connected with the fear around transmission.
- Hughes: How was San Francisco General in terms of openness to different lifestyles?
- Jones: Well, I think it was a mixed bag. I was out as a lesbian. Of the four nurses that I was talking about, there was a gay man and myself, and we both started at the same time. His name was Charles Cloniger, and he came with me when we went to Ward 5B. We were both out.
- Hughes: And did that feel safe enough?
- Jones: No. It was certainly different than it is now. The attitude now is much more supportive, I think. But even now there are parts of the hospital where it's not. I spent a year working in pediatrics in the Maternal and Child Health Division, and it was very different being out in that environment than being out in an AIDS unit. [laughter] I mean, it's like the land of heterosexism up

there. That's the norm; that's the assumption. So then you're really kind of out there when you're out.

You know, it was the 1980s. It was a different era. The gay movement was pretty active in the city. There was still a lot of militancy, and a lot of what you were fighting for was the right to be out. The Harvey Milk thing about encouraging people to come out; you know, individual decisions and all this kind of stuff.

So then patients come in to this environment, and they're outed by virtue of their diagnosis. The assumption was always that they were gay, and most of the time they were, but occasionally they weren't. There were some heterosexual blood transfusion recipients; there were some heterosexual injection drug users.

I remember standing outside a patient's room, and this physician had been called in to evaluate the patient, who had *Pneumocystis*. He said something about this patient needed a bronchoscopy to have the PCP diagnosed definitively. The physician referred to the procedure as having to stick a tube down this fag's throat. This was said in the hallway and was going to go unchallenged if I didn't say anything.

- Hughes: But you did?
- Jones: Yes.
- Hughes: What was the response?
- Jones: He knew he was wrong. It was really inappropriate, but it was sort of like the rolling of the eyes and the whatever. There was still permission to say these kinds of things.
- Hughes: Which wouldn't be true now?
- Jones: Wouldn't now. Absolutely not.
- Hughes: Patients didn't come to the General because it had a more open reputation than other medical institutions in the city?
- Jones: Well, I think that the main issue is that we don't turn people away, and the private sector does, and picks and chooses. The private sector didn't want AIDS patients. So I think that was really it. I don't know that it's so much that it was a question that we were open. Forty percent of nurses at San Francisco General on the inpatient units were Filipino. Culturally, they weren't particularly knowledgeable and sensitive to gay/lesbian issues, nor had the hospital made any effort to educate them,

about the issues facing gay men. So I don't know that it was that conducive and supportive an environment. There were norms and standards in terms of people being used to dealing with a very diverse population, but right under the surface, there was, I think, a tremendous amount of ignorance and homophobia.

Hughes: Why was there such a heavy incidence of Filipino nurses?

Jones: Because we were in a period of very high nursing shortage, and so institutions were recruiting abroad. There are a large number of Filipinos in the Bay Area. The Philippines is a country that really exports labor in a major way, still does to this day, and health care workers are a large sector of the immigrant work force. Plus, there were many immigrants from the Philippines who had fled the Marcos dictatorship. Because there were many Filipinos in the area, then people would come and join families that were here. Somebody would have a job at San Francisco General and hear of an opening, and encourage someone else to apply. There was overt recruitment of foreign-born nurses, and the Philippines had a large pool of university-educated nurses to come to the United States.

Treatment

Hughes: What could you do for a PCP patient in those very early days?

- Jones: The same things that we do now. We don't have anything all that different now. Septra, pentamidine. I think the difference now, and why the survival rates are better, is that it's detected sooner and there's a little more fine-tuning to the regimen and more prophylaxis, but we're not really treating it all that differently. There are a couple more tricks in the bag, but not that much more. In a lot of ways, it's the same drugs that we were using back then, and that predate the AIDS epidemic. People were familiar with PCP from organ transplant patients and other kind of incidences of immune deficiencies that made people vulnerable to PCP.
- Hughes: So you did know how to treat it.
- Jones: Right. People didn't know they were HIV-infected, because we didn't know that HIV caused this. There was no HIV testing. So the only way that people knew that they had AIDS or that they were infected was that they got incredibly sick. So a mild form of PCP would get written off as the flu or a cold or whatever. You wouldn't think to come to the emergency room. So most people were coming in with very severe cases of *Pneumocystis*, highly hypoxic

and quite ill. We would probably see the same mortality rates now if most of our cases of PCP by the time they entered the health care system were as severe as that.

- Hughes: KS is a more visible disease than PCP. You have a lesion, and if it doesn't go away, you begin to wonder about it, whereas a vague cough or whatever symptoms of PCP, as you say, could be written off. But a KS patient with just a lesion you wouldn't have seen. He would have gone--
- Jones: To the clinic.

Diagnosis

- Hughes: So the patients you were getting would be very sick, wouldn't they?
- Jones: Well, they weren't as sick as they are now. The standard at which a patient needed to be hospitalized was much lower than it is now. Mild to moderate cases of *Pneumocystis* are treated now on an outpatient basis. A mild case of *Pneumocystis* back then, once diagnosed, automatically would have bought you an admission, just because that was the standard. If you were anemic, as many AIDS patients are, you would have been admitted to the hospital for a blood transfusion. Now blood transfusions are routinely done on an outpatient basis.
- Hughes: Is that general hospital policy?
- Jones: No, that's because of reforms in health care and attempts to reduce cost. So who got admitted to the hospital was anybody who had symptomatic AIDS, had some kind of symptomatology: fevers, shortness of breath, nausea, vomiting, diarrhea, pain, fatigue related to anemia requiring a blood transfusion. Those symptoms would admit you to the hospital.
- Hughes: The conditions you're mentioning aren't the red-flag markers of AIDS. Could a patient with diarrhea but no other apparent symptom be admitted as an AIDS patient?
- Jones: Well, if a patient presented to the emergency room with out-ofcontrol diarrhea, the patient might be admitted because he was profoundly dehydrated. But then in the course of the workup of the diarrhea, the organism might get identified as one that was part of AIDS. For example, a cryptosporidium, in which case then the person would receive an AIDS diagnosis. And through the medical history, you find out he's a gay man, et cetera, et

cetera, then that's what would buy the person their AIDS diagnosis, essentially.

So people would walk in to the emergency room who had not a clue that they were HIV infected, have some kind of symptomatology, fever or cough, whatever. Pretty early on, people in the emergency room started being able to identify what PCP looked like. If the person was a gay man with PCP, then that meant that they had AIDS and it was part of their diagnosis. The same thing is true of cryptococcal meningitis. The most common opportunistic infections associated with AIDS people could diagnose more easily. So the patient would come in with some altered mental status or absolutely severe excruciating headaches and neck stiffness; they would do a spinal tap and would discover that the patient had cryptococcal meningitis.

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- Jones: Patients received their AIDS diagnosis, having first been diagnosed with the opportunistic infection. But then as the information got out, any gay man who walked in with a cough was suspect of having PCP, or any gay man walking in with a headache was suspect of having cryptoccocal meningitis or toxoplasmosis.
- Hughes: Now, was the emergency room staff learning these conditions through experience--
- Jones: Yes.
- Hughes: -- or were there inservices?
- Jones: Oh, I'm sure there were some inservices early on. I'm trying to remember if anything was said about AIDS during my hospital orientation. I don't think so. San Francisco General is a teaching institution, so there were more grand rounds starting to be presented, et cetera. Massive, institution-wide education I think really didn't start until the AIDS unit opened [summer 1983]. And then the numbers started to really explode, and people fought not to be mandated to take care of AIDS patients, wanting to have the right to wear whatever protective clothing they wanted to wear, et cetera. All of that was happening in 1983, 1984. Those were the years where the standards around universal precautions, confidentiality issues, et cetera, were getting fought out.

Infection Control

- Hughes: Were the guidelines on infection control formulated by the physicians' committee headed by John Conte, predated by the work of infection control nurses?
- Jones: When we started the AIDS unit in '83, Grace Lusby, who was one of the infection control nurses, was centrally involved in the setting up of the unit and the protocols and the standards.¹ They were often called upon when there would be disagreement or debate about what the appropriateness of various infection control measures would be. I don't recall that in 1983 we were using concepts like universal precautions. I don't know what year what became known as universal precautions got rolled out. There was still selective application. You tried to figure out who might have AIDS, and then you fought about what type of precautions were going to be used or not.

But because this was a controversial area within health care and how health care workers were playing out a lot of their fears about AIDS, the infection control nurses were being called upon all the time to mediate these kinds of debates and fights and disagreements.

Hughes: Was the hepatitis B model essentially what should have been used?

Jones: I think roughly. Some of it depended on the nature of the opportunistic infection. So the patient with out-of-control diarrhea, cryptosporidium diarrhea or whatever, you would use what we call enteric precautions, which are often associated with hepatitis precautions. But there were no safety measures in terms of needlestick prevention. There was no routine use of gloves. The contention underlying the whole debate was, Is there any risk of airborne transmission that would necessitate people gowning and masking and gloving when they walk in the room to say good morning to the patient? And there was a wide range of opinion, and people were kind of fighting it out in practice.

> Those of us who believed that there wasn't a risk associated--we didn't have any proof that this disease wasn't transmitted by casual contact, but that was sort of instinctively where we were headed. We were basically role modeling one way of relating to the patients, which was to go in without any kind of precautions. And then other people were saying, "Since we don't know, I'm going to take every precaution. I have children at home; I'm going to take every precaution possible."

¹ See Lusby's oral history in this series.

Fear and Denial

Hughes: Were you afraid?

- Jones: No, I wasn't, and I think there was also a considerable amount of denial. I know there was a considerable amount of denial on all of our parts after the unit [Ward 5B] was opened. We were very adamant that we were going to prove to people that it was safe taking care of people with AIDS. I had eight, nine, ten needlesticks. Any one of those could have resulted in a seroconversion, but the climate or the environment was such that they were downplayed. Any needlestick that people had was more a confirmation that this was not transmitted casually, and it wasn't a risk to health care workers, et cetera. The first occupational seroconversion that occurred at San Francisco General wasn't until 1987, so that denial lasted a really long time.
- Hughes: What was the reaction?
- Jones: People were stunned. We were all stunned. It was just like all of a sudden, Okay, the masquerade is over. We had to fight so hard to have some kind of rational infection control measures, but in truth we didn't deal seriously enough with the real risk of occupational exposure. Our fear was that the pendulum would swing to the opposite extreme and rekindle paranoia and lead to inappropriate safety measures. But actually, the pendulum swung back more towards where it needed to be, which was that there needs to be a balance between adequate safety precautions taken by health care providers versus not taking any unnecessary measures that are alienating to patients. So the seroconversion ended up being the catalyst to be able to rectify the excessively cavalier attitude that we had.
- Hughes: All this post-1987--quite a ways into the epidemic.
- Jones: Yes. And there were documented cases throughout the country of occupationally acquired HIV. We were getting our tests every nine months, and saying, "Oh, got another needlestick." [said casually] It was really nuts. I had profound denial, but who knows if people were really having their terrors in isolation?

Now there's more support. So when people have a needlestick and they choose to disclose to their coworkers or to myself as a manager (which they don't have to) that they've had an exposure, there's more support for people during that period of not knowing if this needlestick is going to result in a seroconversion. Back then, if you had your anxiety attacks, you were going through them on your own, because the collective climate was, This is safe, and to give in to those fears is to give in to the AIDS-phobic, homophobic, discriminatory attitudes out there.

- Hughes: How did getting the antibody test in early 1985 affect the anxiety?
- Jones: I think it did give people a measure of relief, that there was proof. Up until then, there were assumptions, but there was no proof. Everybody enrolled in the health care workers study. Until the test, people were staking out their positions not based on scientific fact.

Of the original twelve nurses who started 5B, six were gay men. Two of them already had symptoms of ARC [AIDS-related complex] or early AIDS diagnosis. So even in the absence of an HIV test, we already knew enough about the syndrome to know that it was likely that they were going to go on to develop AIDS. But the other gay men didn't know if they were infected. So then when the HIV test came out, your coworkers--nurses and volunteers and doctors and whatever--were getting tested and learning whether they were HIV infected or not, or making the decision not to be tested.

- Hughes: Gowning and gloving and whatever one does to protect oneself can look pretty formidable. Was there an esprit de corps on 5B that these patients are traumatized enough; let's not increase the trauma by looking like somebody from outer space. There were at least two motivations, one to keep the patients from feeling further ostracized, and fear for your own safety?
- Jones: Well, that's how the situation got polarized. Those were the two opposite poles, and they were much more polarized than they needed to be. So on the one hand, we were saying, "You don't need to do this; it's alienating to patients; it makes them feel even more ostracized; you're being irrational." At the other extreme, it was, Well, nobody knows how this disease is transmitted. I need to protect myself; I have kids at home; it's my right. So they were totally diametrically opposed.
- Hughes: Even on 5B?
- Jones: No, within the hospital. And then it became certain parts of the hospital versus 5B. Dietary people would bring up trays and wear masks when they would go into rooms (this still happens on 5A to this day). They were challenged or questioned by the 5B staff: "Why are you wearing this mask? Why are you wearing these gloves? You don't need to." Family members that would come in and feel like they needed to space-suit before they went in to see their sons. This was an ongoing struggle.

Our challenging people was sometimes unnecessarily confrontational in some ways, because we had the benefit of all of our years of experience and education and coming to whatever felt correct and right for us. But other people, like the dietary people or the housekeeping people, no one had bothered to inservice or to train them. They were reading all this shit that was coming out of the newspapers that was just wild: AIDS transmitted by mosquito bites, all this speculation.

So they had to make their own decisions based on what they thought was right for themselves and for their families, and they had to answer to their families, when they came home from work. So it quickly took on a very polarized dynamic. There was a certain degree of arrogance and sense of superiority on our part, that we knew the truth. We were rational, nonjudgmental, nonhomophobic, nonAIDS-phobic people, and everybody else was irrational, homophobic, AIDS-phobic, and stupid and ignorant.

Filipino Nurses

Jones: It got racialized really quickly too, because in the hospital the largest ethnic group that was immediately visible was Filipino nurses. It became equated with Filipino nurses, that they are homophobic and AIDS-phobic and will neglect and not provide quality care to people with AIDS. Which was false. There were some absolutely wonderful Filipino nurses and there were some terrible Filipino nurses, and the majority were in the middle, just like it was true of white nurses.

> This is, I think, a very important ingredient in the history of 5B: the twelve nurses who were recruited to start were all white. And in my opinion, that was an extremely serious mistake that took us years and years and years to recover from. It created unnecessary polarization and racialization of the epidemic and fed right into that very complicated relationship between homophobia and racism that is still played out to this day in our communities and in our city.

> So the fact that AIDS-phobic nurses got equated with Filipino nurses, which was wrong, and that high-quality AIDS nursing was equated with 5B and white nurses, was really pretty awful. We were not speaking all in one voice, the twelve of us on 5B. There were some of us who were really disturbed about what was happening and how the rest of the hospital was being viewed, and had enough experience in seeing extremely moving examples of very high-quality nursing care delivered by black nurses, Filipino nurses, Latino nurses, white nurses, straight nurses, gay

nurses, to know that it wasn't just--you couldn't paint the whole picture in one stroke. But other nurses were quite racist, in my opinion.

- Hughes: Was there also another ingredient in this: not only was it white nurses that were doing the optimal AIDS care, but it was <u>gay</u> white nurses?
- Jones: Well, no, because not all of the twelve nurses were gay. And Paul Volberding wasn't, and Connie Wofsy wasn't.
- Hughes: People didn't think, This is not only a gay disease and these are gay patients, but this is essentially a gay unit?
- Jones: I think it did have that character, because the standard was proactive in relationship to gay patients. So the standard that was set was not one where we would merely tolerate, "Come to 5B, your homosexuality will be tolerated." It was, "Come to 5B, your homosexuality, or your lifestyle, or you as a transgender person, will be respected and celebrated." And that was different than other units, so to that extent, 5B was identified as a gay unit. Plus, the gay community really supported it. People would show up in drag on Halloween, or with Easter baskets, or people would bring the <u>BAR [Bay Area Reporter]</u> by for the patients, so it and most of the patients were gay. And I think it's the patients that define the character of the unit.

Quickly, by 1984, we were full all the time, so oftentimes, there were more patients off of 5B than on 5B. When there would be a bad patient outcome on another unit, when a patient would die or a patient would end up in ICU [intensive care unit], and there appeared to be some question of the quality of the nursing care, the way that would get reported by some of the nurses on our unit --we had this one nurse who always used this expression, "The Filipino death squad struck again." Did he have a clue that it was a Filipino nurse? But in some of the units, 80 percent of the nurses were Filipinos. So it was really pretty awful.

The irony was that our unit was set up adjoining 5R, which was one of the intensive care units, and it was the intensive care unit where most of the AIDS patients would be admitted if they needed it. In fact, it had probably the longest experience in caring for AIDS patients of any unit in the hospital, because in the early days, almost everybody with AIDS ended up in the intensive care, usually with *Pneumocystis*. So these nurses had been taking care of people with AIDS since 1980, way before we even came on the scene. Most of them were Filipino nurses, and they provided exquisite care, of the highest standard. The intensive care units at San Francisco General deliver absolutely the highest standard of care that can be delivered and were very sensitive. They were used to working with very dramatic situations, with very dramatic family issues or whatever, and they were very sensitive to those issues.

The ICUs operated off of the model that we came to adopt, which was a very open process, open to whomever the patients identified as their families, who would rally when somebody was really on the brink of dying. It was not only gay patients but straight patients, homeless people, marginalized people. So they had that history of respect for these dramatic moments in life. Many of the ICU nurses were Filipinos. Those of us who were just so offended by this tenor of accusation against Filipino nurses would keep pointing this out.

The thing that escalated this dynamic the most was that four nurses from another unit sued the hospital. This was in 1984, I believe. They sued the hospital saying that they should have the right to wear whatever protective clothing they deemed necessary, and that their rights were being violated by the hospital increasingly coming to some consensus about what the appropriate infection precautions should be.

Hughes: Which were less stringent than these people would have had?

Jones: Oh, absolutely. It was the beginning of the concept of universal precautions, which is what we had been practicing intuitively for one or two years by that point. So they sued, and it made the front page of the newspaper. Three of the nurses were Filipinos and one was white.

> The irony of the whole thing, which some of us kept pointing out, is that one of the nurses' husband, who was a white psychiatrist, was the one who was whipping up the frenzy. He was the ringleader of this whole lawsuit. But all a certain sector of AIDS services saw is that three out of the four nurses were Filipino.

Hughes: How was it resolved?

Jones: I think they lost. They attempted to get some support from the union, and didn't get it, and that was a very important turning point. The SEIU, the Service Employees International Union, was trying to figure out nationally what its position was going to be in relationship to this new epidemic. Their rank and file was asking it to take positions and to defend them, on either side of the debate. So internal to the union, there was a lot of struggle going on.

Luisa Blue

Jones: One of the nurses who played an extremely important role in this whole debate is a nurse by the name of Luisa Blue, who was the president of SEIU local 790 that represented the R.N.'s, registered nurses, at San Francisco General, and was a nurse on that ICU unit that I was talking about that was within the 5B wing of the hospital. She is obviously a longstanding union activist. and also a very progressive political activist in a lot of different arenas. She herself was Filipino and had been active in some of the anti-Marcos work and left politics. She really lobbied within her union for what turned out to be the most organized progressive stance in relationship to the AIDS epidemic. which really set the standard, supported the concept of universal precautions, refused to support the right to withhold care. The union refused to support the nurses who were saying they shouldn't be obligated to care for these patients but also put the obligation on employers to educate their workforce about AIDS and what the real risks were and weren't.

> So that process was going on at the same time that the hospital was fighting out what the standards of infection control precautions were going to be. So all these different sectors were progressing.

> So when those four nurses sued, they went to the union and the union refused to back them up. I think they lost. However, one of the nurses was pregnant, and she had a baby, and the baby had some mental retardation. So she came back again and sued, saying that the mental retardation had been caused by her exposure to CMV [cytomegalovirus], because she'd been forced to take care of AIDS patients. And I think the city settled. It never went to court. I don't remember the details.

Early AIDS Cases

- Hughes: Let me pick up on something you said, which was that the Filipino nurses in the ICU had been treating *Pneumocystis* well before you and the people in your unit saw them. That means pre-summer of 1981, when the first two <u>MMWRs</u> [Morbidity and Mortality Weekly <u>Reports</u>] come out?
- Jones: I don't know when the first AIDS cases appeared at San Francisco General, but they probably appeared in 5R.

- Hughes: I know that Connie Wofsy saw a toxoplasmosis case in February, 1981, that she figures was the first San Francisco General case.¹ He was later transferred to Pennsylvania, and she actually more or less kept track of him. Only later did she realize what she was seeing.
- Jones: Yes.

Well, so these first cases all went to that ICU, 5R. I think they were familiar with PCP because of non-AIDS-related PCP. These were nurses who had really a wealth of experience. They weren't all Filipinos, but the proportion was high. One of the nurses, Martha Ryan, was one of the founders of Health Care for the Homeless. Luisa now works for the regional branch of SEIU and is one of the leading people in terms of their health and safety issues.

Ward 5B, the Inpatient AIDS Unit

Foundation, Summer 1983

Hughes: Could you tell me how 5B came to be founded?

Jones: Well, I heard that the decision had been made to open up an AIDS unit, and that the announcements were sent out for recruiting a staff of nurses to work there. Again, I was working the night shifts; I really wasn't privy to the politics that went on, but later was told that there was considerable controversy as to whether or not it was the correct thing to do.

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Jones: There was a debate over whether creating a dedicated AIDS unit would result in a lower standard of care, or in fact would result in a higher standard of care by creating a specialty unit that would end up helping raise the standard of care everywhere. And as I understand it, the decision involved the university, the hospital administration, but also the Department of Public Health. Merv Silverman, who was the director of public health at the time, and Merle Sande, who was the chief of medicine at San Francisco General but from UC, were intimately involved in making that decision². I don't know at what point in the process Cliff

¹ See Wofsy's oral history in the AIDS physicians series.

 $^{\rm 2}$ See Silverman's and Sande's oral histories in the AIDS physicians series.

Morrison was selected as the head nurse. At the time that I became aware that a decision had been made to start an AIDS unit, he was the person that was publicly representing this new enterprise.

Recruiting Staff

Jones: By then, I had been on 5C for about nine months and had achieved a degree of comfort with my coworkers. We had really created a very good working environment. 5C had a reputation of being a very difficult place to work, and with a very complex mix of patients, and not a very desirable place to come to work. Because we had successfully created this little team, or we'd learned to trust each other, the staff that had been there a long time really started to trust that we really did believe in working, even though we were getting paid so much more than they were. So all of a sudden, it was a changed situation, and a lot of floating, per diem nurses, et cetera, were asking to come there, because it was generally a supportive environment. As a new nurse, I was really learning a lot and finally starting to gain some measure of confidence.

A lot of times there would only be two R.N.'s on the ward, Charles Cloniger, who started at the same time, and I, and oftentimes, he and I would work together. Each of us would be responsible for seventeen patients, and then there would be an L.V.N and a nurse's aide. We had to make out the patient assignments at the beginning of the shift, and we would automatically assign all the AIDS patients to us to be cared for because there was still some level of discomfort on the part of the other staff, and we enjoyed taking care of them. Charles was a gay man; I was a lesbian. We were both pretty insecure in terms of our nursing skills, but we were not insecure when it came to dealing with homophobia. We got a lot of positive feedback from the patients that they felt safe and cared for.

So at the time, we were approached by Cliff and asked if we were interested in applying to come and work there on the unit. There was another nurse on 5C who worked on the day shift, who was a lesbian, Elisa Chandler. She also had been approached or was thinking. We'd been discussing whether or not she would apply. [tape interruption] Cliff said that he had heard our names mentioned in the clinic by patients who had been hospitalized, and they suggested to Cliff that he try to recruit us. Charles and I didn't jump at the opportunity, partly because we were learning a lot on 5C, and we had overcome a lot of the initial awkwardness of being in a new work environment, and things were going well. We enjoyed the variety of patients, and the idea of going into something as specialized so early on in our career seemed not necessarily a good thing.

So each of us actually had several meetings with Cliff. I had been trying to negotiate working part-time, because that had been my goal, because I had a lot of political commitments and I had this small child--I think Annie was three years old at the time--and my head nurse on 5C was unwilling to let me work parttime. So I said to Cliff, "I'll come work for you if you let me work part-time," and he said, "Yes, you can work whatever schedule you want." And that's what did it. It was a very pragmatic decision. And the same thing was true with Charles.

And then there was a certain degree of appeal of being in on the beginning of something and being able to start something. Even though we had limited nursing experience relative to other people, we had a lot of experience working with people with AIDS.

- Hughes: Did you have your own personal view of whether an AIDS-dedicated unit was a good idea?
- Jones: Oh, I thought it was a good idea, as well as recruiting people who wanted to work there. It would be a positive thing, because before 5B it was hit-or-miss for people with AIDS in terms of who you had assigned to you as your doctor or who you had assigned to you as a nurse as to whether or not you were going to get really disgusting care or you were going to get okay care or you were going to get superb care. And things could change from shift to shift. Given who Cliff was and what he was putting out about the type of unit that it would be, it would be an improvement over what the situation was at the time. So that wasn't really a concern.

Hughes: Well, tell me about the very earliest days of 5B.

Jones: Well, there were twelve nurses,¹ one hospital social worker,² two unit clerks,³ and a janitor⁴ were recruited. And they did it in housekeeping too, I believe; people in housekeeping had a lot of issues around AIDS. The word was put out, "We're opening up this AIDS unit. Is there anybody who's interested in being in on this?" Freddy Ramos, a Salvadorian man, said he'd be interested in doing it. And one of the social workers said yes, she'd be interested, and two unit clerks.

Shanti Counselors

- Jones: And then Cliff negotiated a contract with the Department of Public Health to have the Shanti Project have staff counselors on the unit.
- Hughes: That was right from the start?
- Jones: Yes, right at the beginning. There were several weeks of getting the place set up before the unit actually opened and we started taking patients.
- Hughes: Was it logical to know about Shanti?
- Jones: Cliff knew about it, because he knew about AIDS in San Francisco. The nature of that relationship, having a community-based nonprofit come in and have a place as part of a multidisciplinary team was very unique. It was based on a projection or an understanding of what the scope of needs here were: you need skilled clinicians, and you need skilled social services support, because of the chronicity of the needs and the increasing disability, et cetera. And then you need attention to the psychosocial needs of the patients.

- ² Social Worker: Brooks Linton.
- ³ Unit Clerks: Dorry Blakemore, Anne Rome.
- ⁴ Janitor: Freddy Ramos.

¹ R.N.'s: Bob Adrian, Bill Barrick, Elissa Chandler, Charles Cloniger, Lorie Greer, Georges Jalbert, Diane Jones, Kathy Juristo, Steve Keith, Alison Moed, Bill Nelson, Ann Steinlauf.

A Nursing Unit

Hughes: How unusual was it to have a nurse organizing a new unit?

Jones: That's not unusual. Units in the hospital are called nursing units, so they're very nurse-driven. Usually the policy discussions get resolved between the medical directors and the head nurses in terms of admission criteria--those types of policy discussions. But how the unit is going to be organized is usually left up to head nurses to do it. We're starting up a skilled nursing facility at San Francisco General, and it's a head nurse and a nurse educator and a clinical nurse specialist that are really setting it up, and then they dialogue with medical directors. You have to get their cooperation. Usually, it's about admission criteria, standards of practice, or whatever.

Hughes: And that's a joint decision?

Jones: Yes. In our case, our so-called medical directors were Connie and Paul, but the staff nurses were never involved with them. There was some dialogue that went on between them and Cliff and Merle Sande, and I think Merv Silverman. Because this was the first AIDS unit, and the controversy surrounding it, I think there were more people who had their finger in the pot than there would ordinarily be. But Cliff was a very formidable person who had very strong opinions and a vision of what kind of unit he wanted and what kind of people he wanted to recruit. So they fought it out at those levels. He didn't inform us of how controversial the debates were.

> We got recruited, and then he handed the unit to us and he said, "You set it up. You know what you need; you set it up based on what you think is the most appropriate way of doing it."

The Primary Care Nursing Model

- Hughes: Were there certain models that already existed, either in medicine or in nursing, from which you could draw elements?
- Jones: The model that he was using or that he was attempting to instill was that of primary care nursing. So he recruited and he got the hospital to agree to an all-R.N. staff, and not a skill mix of R.N., licensed vocational nurses, and nursing assistants. And the assumption was the nurse was functioning in a primary care capacity, essentially what today we call a case manager, and that the emphasis would be on continuity of care. I think his original

hope was that when a person came into the hospital, he would be assigned a primary nurse, and that nurse would somehow stay involved in the patient's care throughout the hospitalization.

In reality, that's not workable. We have twelve-hour shifts; you work two or three twelve-hour shifts in a row; then you have three or four days off. So that kind of continuity didn't work. But the expectation and the standard was that we would be responsible holistically for the needs of the patients, and that we would play a very central role in coordination. We were care coordinators, essentially. That wasn't terminology that was used back then; that's what's used now.

And that concept did come from other models. All hospitals were moving away from team nursing, the model that I was describing on 5C, where you had one R.N. trying to supervise this whole ancillary staff, and the care was very fragmented. You'd have the nursing assistant doing the hygiene and basic care, and the L.V.N giving oral medications and doing dressing changes, and then the R.N. would have to do care planning and IVs--very fragmented care. Hospitals were moving away from that. In fact, our hospital almost lost its accreditation in 1984 during its Joint Commission on Accreditation of Healthcare Organizations survey. There was a huge purge of the nursing leadership that took place shortly after Cliff was hired. And the hospital started to move away from team nursing towards hiring more R.N.'s and having more of this primary nursing model. So he was on the crest of that wave.

- Hughes: How much of that was dictated by the characteristics of the disease itself?
- Jones: That's how Cliff justified it: this was a very critically ill patient population that had very complex medical needs, but also very complex psychosocial needs, so he needed a higher level of trained personnel to take care of the patients--people who had the training to approach the patient more holistically and understand the interplay between the psychological/spiritual dimension and the clinical needs, and sophistication in handling complex family dynamics and situations.

More on Shanti

Hughes: Was anything drawn from an oncology model, or from a model involving dying patients, where there would be a large psychosocial and family dynamic?

- Jones: Yes. All that came in, and the main vehicle that it came in through was Shanti. So in the orientation and training process, Elisabeth Kübler-Ross, Charles Garfield's work--all of that was incorporated in our orientation and the establishment of early standards of patient care. During our orientation, they incorporated components of the Shanti volunteer training. Their death visualization exercises and the Elisabeth Kübler-Ross stages of dying was all incorporated into the training. We had a week orientation that involved everybody--the nurses and the unit clerks and the janitor and the social worker and the counseling staff. And then there were break-out sessions--
- Hughes: Run by Shanti?
- Jones: Well, people in the leadership of Shanti ran the piece around the death and dying.
- Hughes: And that occurred once?
- Jones: It occurred during this intense orientation, when we were all going through the orientation at the same time.
- Hughes: Before the unit had opened.
- Jones: Yes. Paul came in and lectured about Kaposi's sarcoma, and Connie lectured about infectious diseases, and other people who were emerging as experts in these different fields were part of this week-long orientation.
- Hughes: Did you and others think of Shanti as part of the team?
- Jones: Yes, although it wasn't an easy relationship. It sounded good in principle. But I think there were some problems with the model. The social worker and Shanti were somehow assigned the role of psychosocial team, but yet in our training as nurses, meeting the psychosocial needs of patients was also seen as part of our role as nurses. There were turf issues between the social workers and Shanti. The social worker was resistant to being relegated basically to discharge planner, just making referrals and arranging for transportation, because her training also included providing psychosocial, emotional support. And then Shanti wasn't used to working within a health care institution, so their model and their approach were very different.

Hughes: Had they usually worked in homes before the epidemic?

- Jones: Most of them were trained as peer counselors. There were three of them on 5B.¹ I don't know how many of them were trained therapists. But the model that Shanti is based on is peer support and peer counseling.
- Hughes: Which was not done in a hospital setting.
- Jones: Right, exactly.
- Hughes: Did Shanti come to the person needing care?
- Jones: No, their model was volunteers, right? It was the same model that they have now, in which they would recruit volunteers, train them in providing psychological and emotional support to patients, and then pair them up with a client who asked to have a volunteer. And then the client and the volunteer would meet in the client's home, or they would do an outing together, or--
- Hughes: So it was new to Shanti to be in a hospital setting.
- Jones: But these were not volunteers. The three people who were recruited and assigned to the hospital were paid staff; they were counselors. But the stigma of being a volunteer hung over them. People were used to hearing of "Shanti volunteers," so they would refer to them as Shanti volunteers. So there was always a certain tension in terms of legitimacy.

And then later, as the ward expanded, and there were a certain number of people who were not licensed counselors, their training was really kind of on the job. They were recovering addicts; they were people who had worked as AIDS peer counselors in other settings. Then that question of legitimacy arose. That tension was always there from the beginning, I think.

The crux of it, in relationship to the nurses, was that Shanti saw themselves as taking care of the psychosocial needs of the patients, and yet the nurses felt that was also their turf. So it was a turf issue.

Hughes: Was it ever resolved?

Jones: No, really, frankly not. I think that we learned to live with the tension, at times better than others.

 $^{^{\}rm 1}$ One of the three, Linda Maxie, was an R.N. who later resigned from Shanti and became an R.N. on the AIDS unit.

Patient Advocacy

Jones: The other feature of it is that because the Shanti staff identified as peer counselors, that put a certain role distancing to their actually being part of the multidisciplinary team. So a lot of times when there would be complications with a patient, or a difficult patient, or a difficult family dynamic, if the patient would complain to the counselor about specific nurses or specific doctors, or the institution, or whatever, the counselors would see their role as patient advocate, lobbying on behalf of the patient.

> Which is also the role that the nurses see for themselves as well. Who is your ultimate allegiance to or would you identify with? You cannot function in an institution if you have an adversarial relationship with physicians, social workers, whatever. As a nurse, you need to be a strong patient advocate, but you cannot, as patient advocate, have an adversarial relationship with the physicians. If you believe a physician is doing something wrong or not addressing a patient's pain symptoms adequately, your responsibility is to advocate for that patient, but you're not going to get what you want by alienating the physician, by blaming.

And I think there was that tension when members of the Shanti team were advocating on behalf of the patients. There wasn't always the understanding that you're part of the multidisciplinary team. And it was a hard thing for them to navigate, the us-and-them thing, us the health care providers, or them the patients, or us being the patients and them being the health care providers. Then when they felt disrespected, because they didn't have the right initials after their names or whatever, then it further reinforced their identifying with the patients and creating this false dichotomy between the us and them.

- Hughes: Was there also some tension between the gay and straight issues? Simplistically, "I as a gay nurse have more understanding of the needs of these patients than you, a straight woman or man, could possibly have."
- Jones: I don't think it was very strong on 5A, in part because there were a lot of gay and lesbian employees, and part of the standard was the ability to empathize. The standards were so clear about the ability to empathize, the question of respect, the education and training about homophobia. Occasionally there would be some flavor of that mindset. I think it was more in relationship to the rest of the hospital, not in relationship to the team.

Hughes: Also the initial staff volunteered to work on 5B. If you had problems with homophobia, you wouldn't volunteer. So there was obviously some self-selection.

Motives for Commitment to AIDS Work

Jones: Right. Just like everywhere else in the world in the early epidemic, people had their very personal reasons why they were choosing to do what they were doing. And that was brought out in the initial introductions, and it was a significant component of the orientation and training that took place on the unit. Cliff demanded a degree of self-reflection as to why you were doing what you were doing. That's been part of the standard to this day when new staff and volunteers are being interviewed, questioning people's motivation and scrutinizing whether or not they have realistic expectations.

> People had different stories, and some of the motivations were not appealing to certain people. There was one nurse who was a Christian fundamentalist, and in the course of an interview by somebody who was collecting stories and interviewing various nurses, this nurse disclosed that she was on the unit to take care of the Mary Magdalenes of the world. And you know, as a lesbian, I was totally offended by this. Totally offended. It was like, puh-lease, give me a break.

The condescension that's implied in that statement was not played out in the day-to-day and would not have been tolerated. The standard was very, very explicit in terms of caring based on respect and empathy.

- Hughes: And that was made clear from the very start?
- Jones: Yes.
- Hughes: By whom?
- Jones: By Cliff. Through the self-selection process and the interview process, he brought essentially like-minded people to 5B. There were a significant number of very politicized people. A lot of the principles of the lesbian and gay movement and the women's movement, not so much the antiracist movement, were really incorporated as part of the operating principles of the unit. They were demanded by the patients. The patients were activists, in that sense.

Integrating AIDS Work into One's Life

- Hughes: You said that your reason for going to the unit was a pragmatic one. How soon did it become not just a job, a job that happened to fit into your day-to-day lifestyle?
- Jones: Well, that's a hard question to answer. I think each of us made it fit in different ways and took care of ourselves in different ways. I always had other priorities in my life. I continued to be a political activist. 5B was not the center of my life. When I was there, I gave 100 percent, but when I was not there, I was not there. For other people, it was the centerpiece of their lives, how they were making a contribution.
- Hughes: Was there a realization on your part that you were going to burn out if you had total focus on your job?
- Jones: No, that was because I had other commitments before I went there. So this job was added on as another commitment, and the two informed each other. So how I was growing and learning politically informed the work that I was doing and broadened my understanding of what I was seeing happening, and vice versa.

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Jones: Working with people who were dying was informing my broader personal and political perspective. So 5B was an important piece in my life, but my life had a lot of other important pieces that were happening at the same time. I think it was recognized that we all had different approaches, and that was okay so long as everybody was held and held to the same standard in terms of taking responsibility.

> And quickly we learned that those differences were there. So, for example, Cliff decided as part of the standard of performance and practice on the unit that we would have mandatory weekly staff support groups. Well, that bombed the first time. Nobody wants to go to a mandatory support group, number one. But also, we were all very different. So some were very comfortable with the environment of the traditional support group, and others were not, and that was not what they needed to take care of themselves. They needed to leave work and go to the gym, or on their day off to go hiking, or talk about it at home, or not talk about it at home. Nurses have some similarities, but we're also very, very different in how we take care of ourselves, and that quickly became recognized.

Hughes: So the mandatory support sessions dropped out.

Jones: Right. Now, that's different for social workers and counselors. Their training tends to attract people who really are comfortable in that verbal self-reflection processing experience. So they welcomed the concept of a weekly support group. But with the nurses, it's never worked in the twelve years that we've been trying to make it happen.

> When we interview people now, the other piece we're looking for is how well do you know yourself? How do you handle stress? What is it that you do to take care of yourself? And it's not that we're looking for a set answer, but we need to know that the person has the tools available at their disposal to take care of handling an emotionally and physically challenging job.

Hughes: How do you do it?

Jones: Well, it's changed. Back then, my political activism was a big piece, and I was really burning the candle at both ends. I had a small child. I was practically working more hours as an activist than I was on the unit, so I was putting in eighty-hour weeks. I was part of a community; I was part of a political organization. All of those things provided support. I love the life lessons of working there on 5B, being in these very dramatic transitions that people were going through, and being able to be supportive and caring and learning how people went through successfully or not successfully, kicking and screaming, all the moments that were so packed with meaning. It's very nurturing.

Hughes: How did you manage with a small child?

- Jones: I wasn't a single parent. I was raising her with another woman, so I wasn't 100 percent responsible for her. We lived here [a few blocks from SFGH], and I worked nights. My daughter was in day care and nursery school. I had a supportive community, and my job was supportive. Cliff was very supportive around scheduling stuff for everybody, so I had a very flexible schedule. I was working 80 percent time.
- Hughes: You've now been in the epidemic since almost the first, short one year of its formal recognition. How do you keep engaged now?
- Jones: I'm in a very different role now. I'm manager of the unit [head nurse], so I don't have the day-to-day contact with patients. What's asked of me in attentions and stresses are different than they were back then. All along, the thing that's drawn me the most is the political dimensions of the epidemic and the personal dimensions, all of the questions that it raises about life and death and sexuality and discrimination and drugs and addiction and family dynamics and pain and despair and hope and courage, all of those things that patients and their families and their loved ones

go through. So it's an extremely rich environment to be in, and even though I'm not immersed in it in the day-to-day in terms of intimate contact with patients, it's still the substance of what the unit is.

And now it's a question of the insanity of what's happening to our health care system, fighting to be able to hold on to what has been a center of excellence, fighting to prevent the erosion of the quality of care, because the SFGH AIDS unit is an important symbol in health care about what quality health care should be, could be. So part of the motivation now is the political fight, to save something.

About seven or eight years ago, I was having increasingly more and more back problems, and probably it was about eight years ago I had a very serious back injury at work lifting a patient. I started yoga mainly for back care purposes, and then I have kept on. So I now have a yoga practice which I didn't have twelve years ago, and that makes a lot of difference. Now, when people say, "How do you take care of yourself?", I'll list a lot of things and then I'll add yoga and working in my garden. It's just an evolution as you grow older, things that you learn, slowing down the frenzied pace of the late twenties and thirties. Then as you grow into middle age, the different demands of having a kid, those types of things are what change.

- Hughes: Well, it sounds as though you've been successful in integrating your work into your life.
- Jones: Well, it's integrated, but also the boundaries are clear. It was easier when I was a staff nurse. I bring more stress home now than I used to; it's not a finite job. When you're a staff nurse, at seven p.m. or seven a.m., whatever shift you're working, the next shift comes, you turn it over. So you can beat yourself up as you're walking home, saying, "I didn't do this, I didn't do that, I forgot this, I forgot that, or I should have handled this interaction better." But if you develop the skills to let go, by the time you've gotten home, you let go and your time off is your time off.

When you're a manager, you're never done. It's a lot harder to keep your work compartmentalized, preventing it from spilling over into your life. But it's not the stress of AIDS, as most people think. "How can you do this, working with people who are dying?" I think it's the same stress as if I was running a nursery, or a labor and delivery unit, or whatever.

Early Perception and Causal Theories of AIDS

[Interview 2: December 27, 1995] ##

- Hughes: Diane, I thought we should talk about your earliest perception of the syndrome. I remember you said you were working in the general medical ward, and it was mainly PCP. But were you thinking of it more than just a pulmonary problem?
- Jones: Oh, yes. By then, AIDS had already been defined as a syndrome. We saw cryptococcal meningitis; we saw toxoplasmosis; we saw cryptosporidium. So by the time the AIDS ward was started in '83, in the orientation of the staff, there was a fair amount of knowledge and information, very similar to what we have now, essentially. Maybe there was not as much knowledge of the various facets of AIDS dementia, which emerged as people became more able to survive their first opportunistic infections and longevity set in a little bit longer. Then you saw some patients in the latter stages, including CMV infections which we didn't see as much in the beginning.

But yes, when I came into [AIDS] nursing [1982], there was already an understanding of AIDS.

- Hughes: Also of the underlying immunodeficiency?
- Jones: Yes. We didn't know what organism caused it, but the thought was, it was a virus that was sexually transmitted. That knowledge was already there.
- Hughes: At an early stage, there was also the idea that it wasn't so much what happened to people as what they did, mainly involved with sexual activity. Somehow it was behavior that predisposed people to the disease. Do you remember any talk of that nature?
- Jones: There was a whole lot more emphasis on getting the gory details of people's sexual activity than you find now. It was still in the early days of the epidemiology, so I think that in the history and physical that physicians took, they would make a point of trying to get the patients to estimate the number of sexual partners that they had had, and what types of activity they were engaged in. And the same was true in terms of drug use.
- Hughes: Did you feel that inquiry was legitimate?
- Jones: Well, on the one hand it was, and on the other hand, it felt like there was a fair amount of voyeurism involved. So it took a little bit longer to get to the stage that we're at now. I think the voyeurism and the homophobia played into it. Now, sometimes

on our unit, we don't even know what the risk factor was for the patients. We know if there's active drug use, because that's a factor in terms of their medical history now, but you don't really know if it was heterosexual transmission or homosexual transmission or whatever.

Hughes: Because it doesn't matter.

Jones: It doesn't matter. It matters insofar as you need to know the social history in terms of determining where the patient gets his/her support. At that level you need to know. You don't need to know in relationship to a medical diagnosis.

The CDC Definition of AIDS

Hughes: How much of a role did the CDC definition play in your work?

Jones: There were some cases early on, particularly before HIV testing started, where at the time the CDC case definition was related to opportunistic infections and neoplasms, Kaposi's sarcoma in particular. There were a few patients who ended up on our unit who initially were thought to have one of the opportunistic infections and then turned out not to and then were told they didn't have AIDS. In the absence of HIV testing, that was the best that we could do. However, it was clear that in fact they did have immune deficiency. In the presence of HIV testing and CD4 counts, et cetera, we wouldn't say that any more.

> So the CDC definition did play into it, and it played into it also in terms of very quickly being used as a way to appropriate resources and define eligibility and access to services, discharge planning resources, et cetera. So very quickly, it became this kind of benchmark that gave you access to services or not, depending on what the diagnosis was.

AIDS-Related Complex

- Hughes: Because of resource eligibility, would you be liberal in your definition of what was a case of HIV?
- Jones: Well, very quickly, the category that emerged was one of ARC, which then served to catch all the people who we would now just say are HIV positive. We don't use ARC as a category any more.

- Hughes: Did ARC pretty much revolve around the lymph node syndrome, or was it more than that?
- Jones: Thrush, lymph nodes, fatigue, night sweats--
- Hughes: All of that was ARC?
- Jones: All of those--everything that pointed in the direction of immune deficiency but that wasn't one of the stated opportunistic infections and neoplasms.
- Hughes: Was the assumption that ARC indeed would eventually become fullblown AIDS?
- Jones: Well, it was suspected, but nobody knew. The longitudinal studies were just getting set up. So the type of morbidity/mortality statistics that could be inferred in 1983 versus 1995 were really different. So they would come out periodically, and the percentage of people who would go on to develop AIDS, and then of those, a percentage of people who died, continued to go up as each new longitudinal study would release another set of figures.

And I think there were some people who really thought this was going to be a short-lived epidemic, that there would be a rapid peak to it, and then it would decrease. It would go the way of rapid epidemics. When HIV was discovered, that added a whole new dimension to the longitudinal epidemiological studies. Particularly using the hepatitis studies that were done in the gay male community in the seventies and eighties, they could go back and start attaching a beginning point further back and then track. It just opened up the spectrum.

I don't remember what year the ten-year incubation period became known. But that was an important benchmark, when people started to realize that there was this roughly ten-year incubation period, and that in fact the infections that we were seeing in 1983 were in people who had gotten infected in 1973. We didn't know that at the time.

- Hughes: Well, you couldn't have known that until the HIV test was available. ARC introduced the preliminary idea that yes, this was a spectrum of disease.
- Jones: Right. We had patients who died with an ARC diagnosis. They never progressed to AIDS. That wouldn't happen now, because the AIDS diagnosis in the United States includes CD4 count and other manifestations, like wasting syndrome, et cetera. So we would have patients that would always stay in this category or diagnosis of ARC. In fact, what they had was wasting disease or AIDS dementia complex or conditions in these catch-all categories.

- Hughes: Were you looking at the immunology, at the CD4 counts? Were they part of the ARC diagnosis?
- Jones: We were looking at T-cell counts and helper-suppressor [lymphocyte] ratios. I would say that in the second half of the eighties, CD4 counts became more the standard measurement. And then I don't remember what year the CDC changed the case definition to include CD4 count,¹ multiple bacterial pneumonia, vaginal candidiasis--the infections that affected nongay men and women.
- Hughes: Well, certainly the women's conditions are very recent. That's the 1993 definition.² There wasn't anything that was woman-specific in earlier definitions.
- Jones: No.
- Hughes: Donald Abrams had a category of disease which he called pre-AIDS.³ Was pre-AIDS different from ARC?
- Jones: I don't remember using that category. I seem to remember we used symptomatic and nonsymptomatic. As I recall, he did pretty extensive lymph node studies.
- Hughes: Yes, it was mainly based on lymph nodes.
- Jones: Right.
- Hughes: But there was also a psychological component to it, and I was wondering if that was true also of ARC.
- Jones: Well, you have to remember, this was an inpatient unit, so we got people who were sick.
- Hughes: I should explain what I mean by "psychological." Abrams's hope was that pre-AIDS people would not progress to AIDS. And indeed, they eventually all did. Was there any of that aura around ARC?

¹ The 1985 revision of the case definition refers to "a low number of T-helper lymphocytes or a low ratio of T-helper to T-suppressor lymphocytes." CDC. Revision of case definition of acquired immunodeficiency syndrome for national reporting--United States. <u>Morbidity</u> and Mortality Weekly <u>Report [MMWR]</u> 1985, 34:22-23.

² CDC. 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. MMWR 1992, 41:961-962.

³ See Abrams's oral history in the AIDS physicians series.

Jones: I think there was, but I think it was at a more theoretical level, because when you work exclusively in the inpatient setting, everybody you see is sick, and everybody you see really has AIDS or ARC, with the assumption that it's going to progress to AIDS. I think we made that assumption pretty quickly, because we saw people progress so quickly.

> And it was always interesting to me when I went to conferences that a significant proportion of the body of the conference was devoted to outpatient management, which was working with people who were HIV-infected with no symptoms to mild symptomatology. It was always a rude awakening to realize what part of the spectrum we were working in, which was really endstage, and with 100 percent fatality.

Patients and Staff: Living with AIDS

- Hughes: Everybody you took care of eventually died. What difference did it make knowing that your patients were in an end stage?
- Jones: I don't know for other people, but I think for me, it just became this sense of, This is what's going to happen. [tape interruption] I think it played into a certain degree of fatality and fatalism about it. And I think that's true to this day. I'm very acutely aware when I am out in the community and run into somebody who's HIV-positive, or people living with AIDS, that they are really much more politically and psychically and emotionally oriented towards living with AIDS. And on the basis of my experience, it's much more in the dying of AIDS. And I think that's true of all nurses who have that as a sole experience.

But the other thing that people do to defend themselves is to just deal with what's right in front of you. Now, for example, when I give tours or make speeches or presentations or whatever, I usually say, "We've cared for 5,000 men and women who died of AIDS. That's the beginning of the epidemic at San Francisco General." The staff is stunned when they hear that, particularly the ones who have been there for a really long time. To all of a sudden be confronted with the magnitude of the experience that we've had is really very overwhelming, and it's not something that you can take in when you're coming to work every day. And sometimes you need to.

We had a high school student who did a career placement on our ward, and she was amazingly adaptable in the environment, very uninhibited and interacting a lot with patients. But towards the end of her placement, I was struck by, on her own evaluation, she said, "It wasn't as bad as I thought it was going to be." She saw a lot of people leave and go home. There was a way in which she was making it okay, so I decided I was going to say, "Anne, you need to know that most of the people whom you encountered and that you worked with during the three weeks that you were here will die within the next year, because that's how sick they are." Then her eyes got really big.

So I think since the very beginning, there was some of that element, the bias being that we were really interacting with people at endstage of the illness. Although there were always some patients who lived for a really long time, beyond the statistics. It creates a unique place within the scope of AIDS health care providers when you only have that experience. I think somebody like Donald has a broader experience, because he sees people who are HIV-positive, who don't have AIDS, and then sees them over a longer period of time.

Hughes: So he sees more of the disease spectrum.

- Jones: Yes.
- Hughes: You and the rest of the staff take care of people who are going to be dead within a short time. How has your practical and emotional care been affected by that realization?
- Jones: Well, in the beginning, the lengths of stay were so much longer, and the patients were readmitted frequently throughout the course of illness. There weren't as many home care opportunities and support, so that people really had to come into the hospital whenever they got sick. People didn't know that much about managing some of these opportunistic infections on an outpatient basis. So the tendency was to admit, and admit until the patient either got better or died. So we were with patients for a really long time. The structure of the unit, particularly having the Shanti counselors and the social workers and the nurses there, was that you had a long period of time in which you interacted with patients to move through the cycle, both in terms of clinical care and also the emotional, psychological, spiritual process that the patients and family members had to go through.

It was a very gradual process that had dramatic moments, like when the family of origin, which had repudiated the patient eight years ago, flies into town and now there's a reunion. Or even individually, patients coming all of a sudden to the realization at a very deep level about what was happening to them.

I was working nights the first few years I was there, and I remember a patient whom we knew very well and whom we had on the ward several times, a very young man. He's the patient that's on

the front of that <u>Chronicle</u> magazine¹--Bruce Schneider. He called me up from his house at two in the morning, and he was sobbing hysterically on the phone. I answered the phone, and he said, "Oh, I'm so glad you're there. I was hoping you were going to be there." He couldn't sleep, and he was watching a movie, and there was a commercial that came on for some kind of IRA or mutual retirement fund. All of a sudden it hit him that this was never going to be an option for him. He wasn't at home in hospice; he had gotten over PCP, and he'd lost weight. This was probably 1984. He knew and we knew that he was probably going to die of this.

I'm sure that we had talked about it in previous hospitalizations. But there was just a way in which it really hit him emotionally. And that would happen to everybody, as human beings. We don't just go through a very linear process of awareness. It just happens in fits and starts.

The Effects of Shorter Hospital Stays

Jones: That's a very different experience than the experience we have now, where patients are there [on 5A] for six and a half days on the average. They may be hospitalized only once in their entire illness, and most of the management is going to be on an outpatient basis. So the drama of it reminds me a lot more of the drama of being a labor and delivery nurse, when you're interacting at a very dramatic moment but for a very short period of time, less than twenty-four hours. But a lot of nurses will remember patients, and patients will remember the nurse, even though the interaction was really short, because of the degree of the drama and intensity of it. So a lot of the clinical, psychological, emotional, and spiritual work that you're doing is working much more at points of crisis all the time. So it's a much more intense environment than it used to be.

> And then you add the logistics of moving people out so rapidly. I think that's what makes nurses nervous now in this environment, that they can't do justice to the seriousness of what has to get confronted, because they're caught up in a phenomenal amount of activity, and things need to be done quickly. Would a patient ever feel comfortable saying to his nurse, all of a sudden they realize they're going to die or whatever, and they want to talk about it? Especially during the daytime, very few patients

¹ Life on Ward 5B: From Castro Street to San Francisco General, the Story of the AIDS Epidemic. <u>This World</u> section, <u>San Francisco Chronicle</u>, January 15, 1984.

would even think of doing that, because the nurses are just racing around. It occasionally will happen at night.

Hughes: What are the resources, now that Shanti is gone?

Jones: Most of it has been shifted to outpatient. I mean, that's what we try to do, because people are there [on 5A] for too short a period of time, and the whole time they're there, they're going to diagnostic tests, and there's just a lot of activity. There's not down time with relatively stable patients who are being treated for an opportunistic infection. That's when a lot of the psychological work gets done. Right now, we have people who are very sick, medically, and that's the priority in the short period [they are on 5A]. No one else can do that work. That's our job; we have to do that.

> So when outpatient community providers say, "What's going to happen? Shanti's not there," we say, "Even if you were there, your patients are never in their bed long enough to sit down and have a conversation with them." So we've been trying to encourage outpatient community services, organizations, to figure out how they can provide at home or in clinics the work that was traditionally done in the hospital.

- Hughes: Even though people are getting tests here and there, that doesn't prevent them from having psychological needs.
- Jones: Right, exactly.

Hughes: And yet, there's nobody really there for those needs.

Jones: Right. I think it's more stressful, because you know that that's true. But then the other thing is, as we know as human beings, if you don't really address what's going on, people are going to act out. It's going to come out in other ways.

Hughes: And do you see that?

Jones: Oh, you see it all the time. When I get pulled into a dispute that's going on between a patient and a nurse, more often than not, it's because of something that's going on with the patient that they really haven't had an opportunity to talk about.

> I remember one patient really dramatically. The nurse was profoundly disgusted with this patient because there were a lot of issues of control: "No, I'm not going to go for the test now; I'm going to go later," "No, you can't do this for me now." He was making it impossible for this nurse to provide care, in addition to all the other patients he had to care for. So they just had this huge blow-up at the beginning of the shift, because it was

the third day that this was going on. So I went in, and the issue was that the patient's lover was in Hillhaven Nursing Home, and there was no phone there, or they weren't letting him use the phone, so he had no way of communicating with his lover, and he was just beside himself. I asked a question that kind of led into it, and once he said it, he just burst into tears, and then the tension was broken. Then it was like a whole other human being that you were dealing with.

It's that kind of thing that you see all the time. And sometimes, you can break through it, and sometimes you can't, so you never really know what is happening. Does the patient have enough insight to be able to realize that that's what going on with him or her? Do we know how to ask the question the right way?

- Hughes: So the holistic care that was being given in the early days, both in the unit itself and also in terms of community services, has now shrunk to a more traditional model?
- Jones: Well, I wouldn't go that far. I think it's more a question that the spectrum of the illness--

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Jones: --is narrower. Within that narrow spectrum, the philosophy and the approach is still holistic care. You'll get more holistic care on 5A than you'll get on another unit or in other hospitals. You're interfacing with the patient during this extremely dramatic time, but for a very small period of time. And so there's less of it. But I think the approach is still there. [tape interruption]

> The difference is that back in '83, there were very acute clinical things that we had to deal with. People were in clinical crises, where we were interfacing with the patient. The difference is that after they got out of their clinical crises, they were still on the unit. Now, once they're out of their clinical crisis, they're discharged.

Holistic Patient Care

Jones: There is a holistic way to interact in a clinical crisis and a nonholistic way to interact. [tape interruption] Most of the health care system has interacted in a nonholistic approach-you're having a heart attack, so we're just going to look at the heart. I think people are trying to change. The standards across the board are evolving and changing. But I would say on 5A, people still get a holistic approach to care. It's just that we don't get the experience of a more measured interaction with patients. We're constantly in that acute mode. Some of what used to happen on 5A now happens at Ward 86, and we're trying to encourage the clinic to do more of it. We need them to address things like code status, advanced directives, conversations about at what point are they going to start filling out hospice applications, et cetera. All of those things would be a lot better if they were addressed within the context of the relationship that patients have with their primary care provider on an outpatient basis, not when they're in a crisis.

- Hughes: But that has not been the pattern?
- Jones: Well, it's shifting; it's slowly changing. The only positive thing that's coming out of the changes in health care is people are trying to understand the concept of primary care in a better way. It's really important not to romanticize what went on in the early days of the epidemic. It was really horrible that twentyfive-year-olds had to make decisions about advance directives when they couldn't breathe. They were in the middle of a totally acute, life-threatening case of PCP, and we were asking them to make these decisions. It was just so cruel that they were in that position.

So some of this shift is really good. No matter how much and how good the care is that we provide in the hospital, given a choice, patients don't want to be there. They would rather be home. And that's something that's important for us to remember. We did a patient satisfaction survey last year, and the final question in this long list of questions was, "Given a choice, would you return to San Francisco General for your care?" And the first three people that we piloted this survey on just howled at that question. They were like, "Given a choice, I wouldn't want to go to any hospital! What kind of choice is that?" The first nurse who encountered that reaction got a little affronted, and they felt like, Oh, my god. And then we had to realize that we work in an environment that most people would do anything to avoid. And then once patients are there, yes, they appreciate the care that's provided.

Relationship of Wards 5A and 86

Hughes: Is an attempt now to have more coordination between the AIDS Clinic and 5A?

Jones: Oh, absolutely.

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- Hughes: From what I understand, the relationship hasn't always been smooth.¹
- Jones: No. It was thought to not be necessary. But when you're discharging people who are as sick as our patients still are when they're discharged, you have to coordinate with the clinic. Several times a week we have people from Ward 86 sit in on our psychosocial and discharge planning rounds. And it's much more beneficial, because we all get a much more rounded view of the patients than what we see, and then there's more continuity. So when the patient is discharged and is followed up in the clinic, they have an understanding of what happened to the patient while he was in the hospital.

AIDS Services in Other Clinics

- Hughes: Is it automatic that a discharged patient is followed up in 86?
- Jones: No, not necessarily. The majority are. Ward 86 follows about 3,000 patients, and there are about 300 that are followed in the general medicine clinic, and about 100 that are followed in the family health clinic, and then the district health centers--Health Center Number One on 17th Street and Tom Waddell Clinic down in the Tenderloin.

So if patients don't have a provider, we'll tend to send them to 86, but even that should change. We should really ask them where they want to be referred. If they live in the Tenderloin, it might be more convenient for them to get referred to Tom Waddell Clinic.

- Hughes: Where the care is comparable?
- Jones: Yes. It's a little bit harder for the district health centers and the general medicine clinic and the family health center to manage really endstage patients, primarily because a lot of times their care involves a lot of consultation specialists, for example, ophthalmologists for management of CMV disease. And those are only found at the "mother house", San Francisco General. So sometimes towards the latter stages, or if patients need complex chemotherapy or whatever, their care might be shifted to Ward 86. It's a more comprehensive clinic. But Tom Waddell Clinic follows patients that are incredibly complex, because so many of their

¹ For more on the relationship, see the oral histories in this series with Gayling Gee, Clifford Morrison, and Gary Carr.

patients have overlapping psychiatric and substance abuse problems.

- Hughes: Tom Waddell Clinic became essentially an AIDS clinic, or does it deal with a range of problems?
- Jones: It deals with a range, but they follow 500 people with HIV disease.
- Hughes: Do the providers there and also in the AIDS Clinic look upon what they do as primary care?
- Jones: Yes.
- Hughes: From the start, they were providing primary care?
- Jones: Well, other than family medicine, whose program was designed consciously around defining primary care, I think health care didn't know what primary care was. [laughter] So it's an evolution in that sense. The UC faculty that practiced out of Ward 86 were specialists--oncology, infectious diseases, hematology, et cetera. As the tides shifted and primary care became the wave of the future, then I think they came to the realization that in fact that's what they were providing. Because they were providing for the totality of their patients' needs. But there has always been some tension between the family medicine department and the Department of Medicine, in part around that question.
- Hughes: Family medicine feeling that it should be the prime provider of primary care?
- Jones: Well, family medicine providers have traditionally been looked down upon because they're kind of the general practitioner, the G.P.. Basically what the program was churning out was general practitioners. So they felt they were being looked down on. But on the other hand, they also felt that they were perfectly capable of providing primary care to people with AIDS, and that people in the AIDS division were setting the standard too high for the quality of AIDS primary care. And that tension is still there now, and it's getting played out when you go in to negotiate managed care contracts. Who is it that you're designating as primary care providers?
- Hughes: Is there a lot of negotiating around that?

Jones: Oh, absolutely.

Hughes: That's an issue of the last very few years, isn't it?

- Jones: Well, the tension with family medicine has been there since the beginning. But this issue with the managed care question, yes. Well, the whole concept of managed care is a new concept.
- Hughes: How integrated in people's thinking were these various conditions that eventually added up to AIDS?
- I think by '83, they were. Not completely, but I think yes in a Jones: place like San Francisco. Now, if you were in Omaha, Nebraska, even to this day -- Okay, if you were a gay man walking in with a reported two weeks of fever, weight loss, night sweats, and shortness of breath, a general practitioner in Omaha would probably now think, AIDS or HIV infection. They wouldn't have necessarily back then. If you're a woman walking in in Omaha, Nebraska, and you've been married, and you report five bouts of vaginal yeast infections in the last year, they'll just end up prescribing an antifungal. Even in San Francisco women have to beg for an HIV test over and over again. So we're still living with the legacy of the stereotype--it was not only a stereotype-with the reality of who first came down with this illness. That kind of put a stamp on it.

But I think at San Francisco General by '83, people pretty much all over knew the syndrome. But it was because 90-plus percent of the patients were gay men, so it was very easy to have it pop out at you, and then understand the syndrome.

- Hughes: Were specialists, such as Volberding in oncology or Wofsy in ID [infectious disease], by 1983 realizing that they couldn't function just as an oncologist or just as an ID person?
- Jones: Yes.
- Hughes: They had to function as an AIDS doc, whatever that meant.
- Jones: Right. And they already were.

More on Ward 5B

Discharge Planning

- Hughes: Tell me about the internal organization of the inpatient unit.
- Jones: In terms of nursing, we were always set up with twelve-hour shifts, so we had change of shift rounds at seven in the morning and at seven at night, where each shift would pass on the patients

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to the oncoming shift. And then we had psychosocial rounds three times a week and discharge planning rounds once a week. The psychosocial rounds included the social workers, the counselors, and the charge nurse. And then the discharge planning rounds included community providers. I actually don't even know when those discharge planning rounds started. So it could have been that the community discharge planning rounds really didn't start until after we moved to 5A, which was 1985.

As the community services were getting up and running, we had to create an organized way in which their interfacing with the hospital would happen.

Hughes: Before that, discharge planning was on an ad-hoc basis?

Jones: I think the issue would come up in the psychosocial rounds. I worked nights the whole time we were on 5B, so I don't remember. Steve Keith would know. I don't know when the formal discharge planning rounds started. But the interesting thing is that now this differentiating between psychosocial rounds and discharge planning rounds has just collapsed, and we do psychosocialdischarge planning rounds three times a week. We've cut out the outpatient community providers, because they can't come into the hospital three times a week. And it's worthless for them to come in once a week, because they've missed many of the patients.

Hughes: How do you establish which services are needed?

- Jones: Patients are interviewed and/or assessed. Based on what they need and/or want, referrals get called in. I call on referrals.
- Hughes: And that works well enough?
- Jones: Yes. If the patients know that they're hooked up to a given service, which they don't always know, we'll ask, "Do you have a case manager?" and they'll say no. Well, it turns out they have three.
- Hughes: Because nobody's told them that they do?
- Jones: Well, they don't understand it; they forget--whatever. There are a lot of problems in the coordination of services in San Francisco.
- Hughes: Now, do other units have discharge planning?
- Jones: They are supposed to. It's a standard in terms of accreditation of hospitals. But they don't have the psychosocial team that we had. They didn't have AIDS-specific social workers. They didn't have Shanti counselors, et cetera. So it makes it a little bit

harder, I think. Even to this day, this is the thing that we are known for. In the last accreditation inspection, which was at the beginning of December, the inspectors wanted to meet the multidisciplinary teams, and a lot of the other units had to piece together this team that really didn't know each other, that really didn't function as a team. And clearly, we functioned as a team. That's one of the strengths of the model that we operate off of.

Hughes: But that reflects actuality, does it not? Indeed, AIDS medicine does rely more heavily on community services.

The Medicine Teams

- Jones: It has to be multidisciplinary. And I think that tradition was set in place in 1983. And then rounding with doctors. We've always been within the UCSF teaching model residency program, so there were always a multiplicity of teams of physicians, and rounding with them.
- Hughes: Nurses were expected to be part of rounding?
- Jones: Yes. Logistically it was difficult and continues to be difficult, because there were so many teams; we have ten different teams that admit to our unit. So if five of them show up at the same time and you have four patients and they're on four different teams, you can't really round with everybody.
- Hughes: Are those specialty teams?
- Jones: No, they're internal medicine. Back then, there were eight medicine teams. You were on call every third night, and so if a patient was being admitted during that twenty-four-hour period and your number was up, you were the team that admitted that patient. And that's still how it operates.
- Hughes: How much were physicians a presence on 5B through 1984?
- Jones: Well, the residents were a presence, in terms of managing the patients, and then the attendings, the faculty, were there because they had to be brought in around resuscitation orders and decisions whether or not to go to ICU, et cetera. But they weren't involved in the operations of the unit. They weren't involved in the design of the unit. They weren't really involved that much in the training of the staff. It was very much a nursing-run unit.

A Nursing Unit

- Hughes: More so than comparable units?
- Jones: No, not more so. The difference was that we were given permission to take charge of the unit, which on other units, the nurses didn't necessarily do.
- Hughes: Because they weren't allowed to, or they didn't ask?
- Jones: Because it wasn't part of the tradition.
- Hughes: There was more nursing control on 5B?
- Jones: Right. It was designed and the systems were set up and the standards were set by nurses, and to this day it continues to be. We're constantly pushing to increase the standards around pain management and symptom management and those kinds of things, or really have that kind of voice. And that continues to be different than other units. If a patient on another unit says to a head nurse, "I've been complaining of pain, and my nurse won't give me anything for my pain," and the head nurse goes to the nurse and says, "What's the problem?", and the nurse says, "Well, the physician only was willing to order X, and it wasn't enough," then that is usually the end of the conversation.

On 5A, if a nurse were to say that to me, then I would consider that he or she were not doing their job. They have to continue working with the physician and with that physician's supervisor and the supervisor of that supervisor, until they get satisfaction for the patient. So the role of patient advocacy from the very beginning was very central to the role of the nurse, which then gave 5B at its heart the character of a nursing-run unit.

Hughes: Was that an explicit part of the orientation?

- Jones: Yes, I think so.
- Hughes: Was it unusual for Cliff Morrison, a nurse, to have such a strong role in setting up a unit?
- Jones: Well, no. Other units have been established at San Francisco General since then, and they really are nursing units. They're called nursing units because they are nursing units. So I don't think it's that; I think it's the approach that he took. The difference was between what I saw him do and what I've seen other head nurses who have started new units do. Cliff turned it over to the staff very quickly. He set the orientation; he selected

the staff, and then he turned it over to us and said, "You all decide how you're going to run this thing, and what works for you."

So, for example, he took those of us who already worked at San Francisco General, who knew the systems in terms of how you stock your narcotics, how you get the equipment that you need or whatever, and said, "You design how you want your medication room to be set up, and I will order what it is that you want, and I will fight with whomever so that you get it." He did that very quickly, and I think that was, in a lot of ways, his genius. It wasn't even that he set it up; it's who he selected and the overall philosophy and approach that was to be taken, and then turning it over to the people who were actually going to be doing the work and supporting them and lobbying for them.

So Cliff would fight for standards around cleanliness and that kind of stuff. When we wouldn't get cooperation from a hospital department, we could go to him and he would lobby for us. But by and large, it's the staff that really ran 5B, and that's true to this day, too. So the tradition of the manager is not one of micromanagement. It's very difficult for me when there's a staff person that has some kind of performance problems, because I'm not in the orientation of monitoring what people are doing. So much of the standards are maintained through peer pressure and peer support by the staff; it's not a top-down kind of thing. And Cliff set that tradition.

- Hughes: Are you consciously following it?
- Jones: Am I consciously following it? I agree with it, which is why I took the job. [laughter] I think it would be very hard for someone with a different philosophy to try to change that. It would be foolish. I think it's one of the reasons why you have the quality that you have and have had. But you'd also have mutiny. The unit attracts people who like to function in that manner. They like to take a lot of responsibility, and they do.
- Hughes: Yes. How does this play in, if at all, with the tensions with the AIDS Clinic? 5B is a very strong nursing unit, and the AIDS Clinic is a UC physician-dominated operation.

[interruption by Jones's daughter Annie]

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Jones: There wasn't much of a presence. When the patients were admitted to the hospital, they weren't really followed by their primary care physicians or a nurse practitioner, so we didn't really see them much. There wasn't much interaction. Hughes: They were two separate operations.

Jones: Yes.

Patient Advocacy

- Hughes: In hiring nurses, was willingness to be a patient advocate one of the criteria?
- Yes, and to this day it still is. But see, I think some of it was Jones: conditioned by the environment that we were in, where there was so much stigmatization and prejudice against people with AIDS, that if you made the decision that you were going to work in this field, that automatically meant that you had to have some of that orientation. So in the same way that you were willing to go to bat for your patient around effective pain management, or appropriate decisions regarding life support or whatever, you were also going to go to bat with the hospital personnel who were insisting on wearing gloves when they went into a patient's room or a mask when they didn't need to. Which still happens to this So that's still an expectation, as well as expecting that we day. were going to prevent violations of patient confidentiality. So there is that element of very explicit advocacy that I think is framed by the politics of stigmatization.

Patient Confidentiality

- Hughes: I understand that patients for some time were listed on the board by their first name only, and that later was changed. Can you tell me about that?
- Jones: The reason that practice was started is because in the beginning of the epidemic, there were just lots of violations of confidentiality and privacy. As word would get out that another person got sick, and another person "got it," people would come to the ward looking for who was there. And that was something that we always had to be on the watch for. So that's why we did that, and patients really wanted it.

And then what started to happen was with the shorter lengths of stay, and when we moved to 5A, it was becoming really hard to keep track of patients. There'd be five Michaels and three Juans, and we started to have potential errors, people getting sent for the wrong procedure and the error getting discovered at the last minute. The radiology department would call up and ask for somebody, and the unit clerk would be sitting there trying to figure out who it was that they were talking about.

Hughes: Yes, I can see that would be confusing.

Jones: But also, it was that AIDS became such a universal reality in the gay community that it didn't carry the stigma. It's almost like you're an anomaly if you're HIV-negative in certain sectors of the gay community.

> We do still honor wishes of patients who haven't told their loved ones that they have an AIDS diagnosis. Their desire not to be on our unit will be respected and honored. And a lot of times, that is what makes patients not want to be cared for on Ward 86 but in one of the general areas of the hospital.

Hughes: Then you are not responsible for those patients?

- Jones: Right.
- Hughes: They're cared for exclusively--
- Jones: Yes, on the other unit.
- Hughes: What about the physicians?
- Jones: It's the same physicians. It's these medicine teams.

In this past year, we started admitting oncology patients --

- Hughes: Straight oncology, not AIDS?
- Jones: Yes, not AIDS oncology. If somebody will call up and say, "Is this the AIDS ward?", 50 percent of the time we might say yes, 50 percent of the time we'll say, "Well, this is a medicine unit." I mean, a flag goes up if a caller is trying to figure out what a patient's diagnosis is. So it's tricky.

This morning a visitor asked another head nurse who was visiting me, "Is this the AIDS ward?" and he said, "Yes." And I knew that he had just gone in to see a patient who had cancer, and I said, "This is a general medicine ward, and there are patients with a lot of different diagnoses here. So don't assume that the person that you went to visit has that diagnosis. If you want to know what they have, you need to ask them. They're the only people who have the right to tell you."

The question of medical confidentiality continues to be an issue. It's a very political issue, too, in terms of reporting

diseases. AIDS is reportable; HIV [positivity] is not, in California.

The Intensive Care Unit and Its Nurses

- Hughes: Is there an ICU on the unit?
- Jones: No.
- Hughes: There's no AIDS-designated ICU?
- Jones: Right. When the ward first started on 5B, there was an ICU on that ward that was a medical ICU, and where most of the people with AIDS were. I think we talked about that the last time: a lot of those nurses really were the ones who had the most experience with AIDS patients.
- Hughes: Yes.
- Jones: So we had a much closer relationship with those nurses, because of the physical proximity and moving patients back and forth and helping each other out. Very quickly, we became known as a very well-stocked, well-run unit, so they could always come and get something from us. And they had the clinical expertise that we could always call upon when we had a very difficult clinical issue that we had to deal with. But now, there are two ICU's in the hospital, and AIDS patients go to one of those two.

Visitors and the Media

- Hughes: When do you remember visitors beginning to tour the unit, and what did they do to the functioning of the unit?
- Jones: Oh, that was from the beginning. Yes, this was fishbowl nursing from the beginning.
- Hughes: Really.
- Jones: Yes, I mean, the hospital went public. I don't know if Diane Miller¹ and Cliff remember it as a conscious decision, strategy, or not, but it seemed to us from where we sat that it was a

¹ See Miller's oral history in this series.

conscious strategy. Once the decision was made from the Department of Public Health that they were going to do this [create an AIDS ward] in the face of the controversy that surrounded it, then they decided they were going to showcase it. So at the opening of the unit, there was a huge press conference, and Dean Edell did his show there, and all the television channels were there. From the beginning, we were practicing nursing under the spotlights of the media. For the Channel 4 piece, "In the Midst of Life," they spent six weeks on the unit filming, with Roz Abrams.

Actually, the photographer was just back this past year covering the day that they had the press conference when we were designated the number-one AIDS hospital in the country by <u>U.S.</u> <u>World and News Report</u>. They did another press conference and there was a big flurry of media. They wanted to come up on the ward and to interview patients and staff. The photographer from Channel 4 had practically lived with us for six weeks back in 1984.

There were some very funny things that happened. One nurse, Elisa Chandler, actually threw Merv Silverman (who at the time was director of public health) off the unit, because he showed up unannounced on a Saturday morning with a whole entourage of people. The floor was really busy and patients were really sick, and the patients had been complaining that there had been too much activity going on, so she refused to let them come on.

Hughes: [laughs] She realized who he was?

- Jones: Absolutely. She was like, "No way. This is first and foremost a nursing unit."
- Hughes: It's not a showcase.
- Jones: It's not a showcase; it's not a museum; it's not a stopping place on your little itinerary. And he was very gracious about it, and he apologized profusely. That attention has been a constant, too, and has fed the unit's reputation, truthfully. I mean, 50 percent of the scoring in this <u>U.S. World and News Report</u> rating comes from reputational score, and you nurture that reputational score by providing access to all these visitors.
- Hughes: And that was a conscious decision, you think?
- Jones: That I don't know. You'd have to ask them. It felt conscious to us. [laughter] It quickly, in our minds, became tied to, This is how we're going to guarantee the resources. When we have to go to bat around protecting the skill mix of the nursing staff or whatever, when I finally understood how the scoring is done of the

<u>U.S. World and News Report</u>, that is how I keep selling it to the staff. Because it is difficult. It's an added stress, dealing with all of these visitors.

We actually had a moratorium during the month of December, when we were going through this hospital accreditation. We were having a phenomenal number of requests for tours, and I called down to hospital administration and said, "I just can't do this. I'm not allowing any more tours until January." They came back to me and said, "Okay, we discussed it with Richard Cordova," who's the CEO, "and he gives his permission and support." [laughs] So it's that kind of little game.

Ward Culture

- Hughes: You've been talking about the culture of 5B/5A. Is there a conscious effort to pass down that culture, and also to distinguish 5A from other units?
- Jones: Well, to answer the second part first, I don't think it's what distinguishes 5A from other units, but it was developed for the purpose of distinguishing it. The culture was developed for two reasons: one is that it led to better patient care, in our opinion, and secondly, to better working conditions, which then, in our opinion, lead to better patient care. If you have a satisfied staff, then you're likely to get a better quality of care.

I think it starts from the selection process of nurses, so the interview process and what it is that we're looking for, the fact that we'll take a chance with somebody who clinically might be a little weak. We might take less of a chance now than in the early days, but in the early days, we would take a chance. Several of the nurses that Cliff selected were relatively new graduates, myself and Charles Cloniger. I was one year out of nursing school. So half of his staff was relatively inexperienced, clinically.

What we were looking for was a degree of maturity and an understanding of what I would call the politics of AIDS. I'm not sure that's what he or other staff people would have called it. But an understanding of discrimination, sensitivity around lifestyle issues, et cetera.

So that tone is set in the screening process, and then it's built into the orientation and the probationary period that an individual nurse or a social worker or whatever will go through, where you're evaluating both their clinical competence, but also what you're calling the cultural aspects. So they're being evaluated in terms of their effectiveness around patient advocacy, sensitivity to patients and families, family dynamics, sensitivity around understanding issues facing gay men, issues facing injection drug users, issues facing people of color or facing women, et cetera. So that's part of the standard that everyone is evaluated against.

And then it gets reinforced through the structures of the unit. In order for these psychosocial discharge-planning rounds to happen and to feed the information into them, the charge nurse has to go around to each individual nurse and say, "Give me an update on your patient." What is expected is not the functional update that you might get if you go to another unit and say, "Give me an update on your patient," and they'll tell you, "His vital signs are stable, or they're not. He has an IV; he can walk; he can't walk; he's getting penicillin every four hours. He's going to have an X-ray, and he's constipated." That's the narrowest kind of functional update.

When I'm getting ready to do rounds or the charge nurse is, I go to an individual nurse and I want as comprehensive an overview of that patient as possible. "This is the patient's first hospitalization; this is what's gone on," including if it's early stage, what their CD4 count is, what their living situation is, do they have a family, how the family is coping, all of those aspects. So that's what's expected. So that structure of the discharge-planning rounds reinforces again the standard.

If a nurse can't give me that information, and sometimes they can't, because they've been off for four days, it's their first day back, it's eleven o'clock, they've had three or four hours to interface with four patients, they may or they may not know. The expectation is by the next day, they will know it, and if they don't, then you work with people to get them to a place where they do.

And then it gets built into staff education, staff retreats, staff meetings, the retooling of the unit operations, how the communication takes place. For example, a big change that took place about five years ago is we redesigned how the change-ofshift report would happen, and it really was set up in order to facilitate continuity of information from shift to shift. The oncoming nurse and the offgoing nurse were communicating directly.

Hughes: Are these methods being used in other units now, both in the hospital and in other hospitals?

Jones: Yes. They're not unique--we didn't make them up. They've been used in other hospitals. We've appropriated things that we think might work, and we try them. It's known that 5A runs smoothly, that there's a high degree of staff and patient satisfaction, so people will come to us and say, "Okay, how do you do your changeof-shift report? How do you do your psychosocial rounds?" We have those things written down, and we can give them and say, "Okay, this is how we do it. This is how we make patient assignments," et cetera. Culture gets reproduced in those ways.

Alternative Therapies

- Hughes: Do you want to say something about alternative therapies?
- Jones: That's, I think, our biggest weakness. There have been none, essentially. It's rare but, on occasion someone's acupuncturist who's been following the patient for a million years has come in, and in fact, the hospital refuses to design a policy that encourages that to happen. I think that the people on 86 probably have a lot more to say about that because of how they're interfacing with patients. By the time patients agree to come into the hospital, they know by and large it's going to be for a traditional, western-medicine, big-gun approach.

But about as close to it as you can get is, you'll ask if a patient takes Chinese herbs or smokes marijuana or whatever. That's not judged and it's just taken at face value. But there's nothing from alternative medicine that's really been incorporated, which I think is a problem. It's a big weakness in the service.

- Hughes: Are you aware of AIDS units elsewhere incorporating alternative therapy?
- Jones: There are many outpatient clinics that have incorporated acupuncture.

The San Francisco Model of Comprehensive AIDS Care

- Hughes: We've been more or less talking about the San Francisco model. Is there any further that needs to be said?
- Jones: I think that the strengths and the weaknesses of the model are reflected somewhat at SFGH. So we see the fragmentation, the duplication of effort, and to a certain extent are part of it. We

can't do whatever it is that's needed to be done to change that. On the other hand, it's one of the reasons why we can get patients out of the hospital quickly. The average length of stay for an AIDS patient in New York City is fifty-five days.

- Hughes: Are you still getting patients discharged faster than other hospitals?
- Jones: Yes. And I think it's because we have visiting nurses and residential hospice programs.

AIDS and the Nursing Profession

- Hughes: What effect has the epidemic had on nursing per se?
- Jones: Well, Cecilia Worth, a nurse on 5A, is going back to the East Coast to take care of her father, who's dying of Alzheimer's. She's a writer, and she wants to write about that. She's actually written some things already, I think. She's scheduled in the last few months a series of getaways with staff to discuss this issue. That's usually the question which she puts to people in a little focus group discussion.

I think the epidemic's had a very positive effect, and the number-one group of people whom I credit for this are patients. People with AIDS, because of the nature of the epidemic and what they had to confront, had to become their own advocates. They pushed and challenged us to respond in the way that we did. They asked for allies, and those of us who did step in and start doing this work were responding to that request.

What it's brought to nursing is a much stronger understanding of patient advocacy, a much stronger understanding of a need to take a holistic approach in the management and care of patients, and to take a very patient-centered approach. So instead of being the ones to tell patients, "This is what you're going to do," it puts us more often in the position of asking, "What is it that you want?" and then helping make that happen.

I think we're learning that lesson in a much deeper and even more complex way with the increasing number of injection drug users that are coming in for care, because it's forcing us in a new way to overcome our stigma and to learn to respect people and to help facilitate the process of their making decisions about what it is that they want. I was doing a workshop at an AIDS conference a couple of weekends ago with J. B. Molaghan, the head nurse of Ward 86, and I was presenting using a harm-reduction model in working with injection drug users. There was a fair amount of hostility in the crowd. One nurse raised her hand and said what was being characterized was all the missed opportunities that health care providers have when we're interfacing with patients who are active drug users, because we can't see past the label of, This is a drug user, and the only choice that we offer that person is, You have to stop using drugs or else. So you get into this revolving door through the emergency room.

She said to me, "Well, what exactly would you do for an HIVinfected prostitute who's a crack addict who shows up in the emergency room?" And she asked this question in a very belligerent tone of voice. I said, "Well, I think what I would do is to ask her what is it that she needs."

When I went to nursing school, if you were presented with a patient labelled IDU [intravenous drug users], you would automatically start formulating a list of problems, and I would start, as a nurse, prioritizing what those problems were and what the solutions would be. The reality is that my solutions may or may not have anything to do with what this woman is interested in or capable of. I think that was true in the beginning of the epidemic, too. So the epidemic has made us more responsive to patients' needs. It's made us learn to be better clinicians, so that we can advocate for effective symptom management. Because the reality is, the only thing that really brings people into the hospital is when their symptoms are out of control. So the quicker that we can bring those symptoms in control, the quicker they can get out and be gone and not have to be in this unnatural environment. So it's given us a different incentive to be good clinicians.

And it's taught people about compassion, and about life and death. Mainly about life choices. When you work with this many people who die at such an early age, it has to change the way you look at your own life and priorities and choices. In a lot of ways because of the politics of the epidemic, it drew a sharp line in the sand, and people had to decide what they were going to do. So it made the choices a little sharper and clearer.

I think it's definitely challenged homophobia, and, to a lesser degree, the racism and class stuff that you see, particularly with the injection drug users. And the sexism, too. The epidemic has thrown the spotlight on how women are seen as a disease vector. They have the tendency to be concerned always about others, about their kids and about their partners. How difficult it is to get them to be concerned about their own situation. I think the list is endless. At San Francisco General, it's definitely raised the standard of care all over. It's really propelled the whole question of advance directives, pain management, hospice, all of those things. You can't have this many young people dying, or dealing with this illness and living with this illness, without massive changes. And it's also forced the question of provision of outpatient services, because the system couldn't afford to provide care like we did on 5B to the tens of thousands of people who are going to need it. It's just too much money.

Hughes: Thank you. Very articulate.

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The San Francisco AIDS Oral History Series

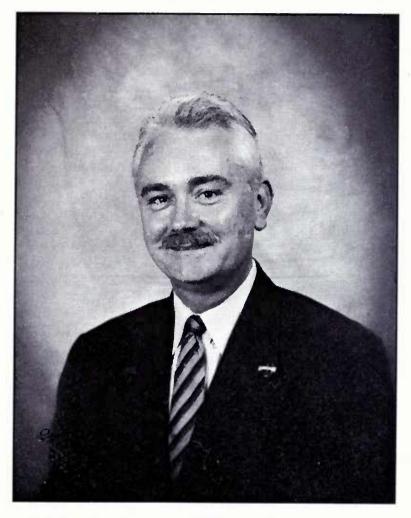
THE SAN FRANCISCO AIDS EPIDEMIC: THE RESPONSE OF THE NURSING PROFESSION, 1981-1984 VOLUME III

Clifford L. Morrison, M.S., M.N., R.N., F.A.A.N.

ORGANIZER OF THE AIDS WARD, SAN FRANCISCO GENERAL HOSPITAL

An Interview Conducted by Sally Smith Hughes, Ph.D. in 1995

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Cliff Morrison, April 1997.

Photo by Olan Mills.

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INTERVIEW HISTORY--Clifford Morrison

Cliff Morrison is a person of many accomplishments. He holds degrees in nursing, hospital administration, and education, and more recently has run his own private consulting service for AIDS-related organizations. This oral history, however, focuses on the role for which he is most widely known and justly proud, initial organizer and AIDS Clinical Coordinator of the first hospital ward dedicated to the care of AIDS patients, Ward 5B at San Francisco General Hospital.¹

From 1983 to 1986, Morrison was at the center of activities related to 5B. He tells in this most personal of oral histories of his own and others' early concern that creation of an AIDS ward in 1983 would be tantamount to creating a leper colony in which patients with AIDS would be isolated. That is in a sense what happened, but in another way Ward 5B was supportive to both patients and care givers. For aside from establishing nursing and psychosocial services tailored to the needs of patients with AIDS, Morrison and the ward staff created a culture in which patients, predominantly gay in the first years of the epidemic, felt nurtured in terms of their nursing, medical, and emotional needs. It was holistic nursing in the fullest sense and vitally important at a time when care was essentially all that could be offered. The unit quickly became a model for enlightened AIDS care, visited in the early years by politicians, the media, and physicians, nurses, and other health care professionals from around the world.

In telling his story of the creation of 5B, Morrison makes quite clear that the so-called "San Francisco Model of AIDS Care" was not planned; it evolved as he and others sought to arrange for the comprehensive and coordinated hospital-based and community services required by often desperately ill patients. First and foremost it was a nursing unit, not a medical unit, and was conceived and run by nurses. Morrison never forgot that nor let anyone else.

He maintains in the interviews that he sought to avoid the swirling politics surrounding virtually every aspect of the early AIDS epidemic in San Francisco; yet his story as told here is rife with political struggle, both internal to the hospital and in the wider community. He tells for example about the contention over infection control policy, a theme of many of the oral histories in the nursing series, and his attempt to distance himself from the bathhouse controversy which raged in San Francisco in 1983 and 1984. He also comments astutely on the impact of AIDS nursing on the profession of nursing. The prominent contribution that nurses played in establishing

¹ In 1986, 5B was expanded and renamed 5A, its current designation.

policies and procedures to deal with the epidemic was eventually translated to other areas of nursing. "I think particularly," Morrison commented in the oral history, "that the role of nursing changed a lot during that period [the mid-1980s], in that for the first time we [nurses] were at the table. We were major contributors to policies, to the decision-making process."

The Oral History Process

Three interviews were conducted with Morrison between January 12 and January 30, 1996 in his condominium on the slope of San Francisco's Diamond Heights. We talked at some length over strong coffee and biscotti before beginning the recorded sessions. Although somewhat of a media star after the AIDS ward opened, Morrison was grateful to have the opportunity of an oral history to expound fully on his experiences and the emotions they continue to raise for him. He reviewed and returned the transcripts with a few changes.

This revealing oral history, told by one who cared deeply about his job but more than anything else about his patients, suggests in highly personal and detailed fashion what it was like to create and provide nursing and other services for patients in a hospital at the center of the early AIDS epidemic in San Francisco.

> Sally Smith Hughes, Ph.D. Research Historian and Project Director

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BIOGRAPHICAL I	NFORMATION
(Please write clearly	. Use black ink.)
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Occupation Decensed	Birthplace Georg A
Mother's full name CARRIE B. Mon	RR:SON
Occupation Deceased	Birthplace Flore DA
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I FAMILY BACKGROUND, EDUCATION, AND EARLY CAREER

[Interview 1: January 12, 1996] [Location: Mr. Morrison's home in San Francisco] ##¹

Family and Upbringing

Hughes: Where did you grow up?

Morrison: In the Florida Panhandle. The town is called Live Oak, Florida, and it's just a little rural farming community, about 4,000 people. I used to always refer to it as literally in the middle of nowhere, halfway between Tallahassee and Jacksonville, at the foot of the Okefenokee Swamp, and the Suwannee River runs right around it. It's a beautiful, picturesque place, but even today there is a lot of poverty. It's the poorest part of Florida, about twenty-five miles from the Georgia state line. I used to say to myself, "Oh, thank god I was born twenty-five miles south." [laughs] Because it sounds so much better to be able to say I was born in Florida than Georgia. [laughter]

> A large family, and no one in my family was educated. My father was an alcoholic. The typical story that you hear about the Deep South, I mean, all of the craziness, dysfunctions in the family, very strong mother who managed to keep us all together, and who wouldn't divorce my father, because she's Catholic and because it's just not something that you do. She married him for life, and all of this. But it was difficult, to say the least.

 $^{^{1}}$ ## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Hughes: How many children?

Morrison:

My mother actually had seven, and five of us--well, actually, my mother had six. One died, and then there was a half-sister. My father had an affair somewhere along the way, and there was a half-sister. I really don't remember her, and I've often wondered what happened to her, because she disappeared at some point in my life. Now both my parents are dead. So that part of my life kind of got lost.

It was certainly bizarre and dysfunctional, and in poverty; we literally lived in a shack. We had no car, no telephone, no television. It was pretty rural. In the latter part of the twentieth century, people didn't live that way. Well, they did then, and I think they still do to a large extent. All you have to do is just go to the rural South, and you'll still see it everywhere. There are a lot of poor people, a lot of poor white people as well as people of color.

So I grew up with that, and didn't really think too much about what I could do or what I would need, because there weren't role models for me. Nobody went to college; nobody in my family had ever finished high school, so there just weren't any role models for me. My earliest memories were that I was very different from anybody else around. My mother, I think, identified that as well.

Years later, in talking with her before she died, I remember saying to her, "You knew that I was different. I always knew that you were aware of that." And I wanted to know at what point she knew. And she said, "I always knew. I could never really quite put my finger on it, but I knew from the moment you were born that you were different from all of my other children, and I couldn't really understand why." So it was difficult, but I think I certainly grew up kind of as mama's boy. But because of dysfunction in the family or whatever, I lived with relatives, and my grandmother for a while. Then at the age of ten I lived in a foster home for six years, because I couldn't get along with my father. Then I came back home and lived with my mother and my father my senior year in high school, because my father was getting a lot sicker at the time, and because I was so close to my mother, I wanted to spend some time with her before I left.

I decided I wanted to go to college. Everybody just kind of humored me with it, because it was not something that anybody had done. I remember after I was enrolled in college saying to my mother, "Aren't you proud that I'm in college?" She said, "All I ever really wanted you to do was finish high school." That was her expectation. She just never had an expectation that I would go any further.

Hughes: Why did you?

Morrison: I think realizing how different I was. I was a bookworm, and I turned inward. I read everything I could get my hands on, and a lot of things that I shouldn't have read. But certainly I was fascinated by it. I was an avid reader, and took a lot of ribbing for that, because where I grew up, you either worked in the fields or you were an auto mechanic or a carpenter, and there really wasn't anything in between. So I was the frail little sissy who was always crying and always running behind my mother, because I didn't like working in the fields, because it was cold in the morning, or I got too much dust on me.

> I used to have to work in tobacco, and I remember standing in front of my mother and saying, "Look at my hands! I can't believe my hands!" And she'd say, "Well, you'll have to get over it." And I'd say, "One day, I'm going to have a job where my hands won't look like that." I remember she used to laugh and she'd say, "Oh, yes, yes."

I remember I said to my mother once, "I'm going to have a house one day that will have central air conditioning and central heat. It will be so that any time of the year, I can walk around in my underwear if I want to." And I remember my mother looked at me and started laughing, and she said, "Well, you'd better get busy." [laughter]

But I think I also knew from my earliest recollections that I was gay. I didn't know what that was then, but looking back on it, I know now that that's what set me apart and certainly made it very different for me. I remember reading something several years ago, and I always thought that this was fascinating. I've always wanted to do some research on this. Apparently, gay people have more vivid memories of their youth than other people do, for whatever reason, the trauma associated with it or whatever. I've been surprised in talking to a lot of gay people that they actually remember being babies, and I do too.

I remember being an infant. I remember lying in an old baby bed, wanting to be picked up, and wanting to be held by a man. When women picked me up, I would cry. I remember being two and three years old and following around, trying to get the attention of males. So yes, I grew up feeling that I was very different, and by the time I was seven or eight years old, I looked around and thought, What am I going to do here? I'm never going to survive in this environment. This is just not for me.

So I withdrew and really went into a dream world. I think I spent most of my years growing up learning to survive, and the way that I did that was that I turned inward and fantasized. I remember by the time I was eight or nine, I would go out in this back field behind our house, and I had in my mind that I was going to live in a big city in an apartment, and that I would live alone, and that I would have my own bathroom. It's amazing the things that I would think about, that say a lot about what people need. I would have a car, and go to parties, and I would socialize with people, and I wouldn't live like this, because this was so dirty, and this was not how I wanted to live. So I grew up with that, and I didn't share it, because every time I would bring up something like that, I'd get laughed at. So I just knew within myself that I had to do it.

Even as children, we always had to work, because we had to help put food on the table, because there was just no money.

Hughes: You worked on the property, or for other people?

- Morrison: For other people. We had some of the worst land in the county. It really wasn't enough to farm; it was rocky sand, so there was nothing there.
- Hughes: But your father was a farmer?
- Morrison: No, my father never was a farmer. My mother's family were farmers. My father's family were actually professional people. As I got older, and particularly by the time I moved out here, people used to say, "Oh, you must have grown up southern aristocracy." I used to really enjoy the fact that anybody would think that. But my father's family kind of was that. I've often compared my father's family to the old Dickens story of <u>Great Expectations</u>, and I think of Miss Havisham--I don't know if you know <u>Great Expectations</u>?
- Hughes: No.
- Morrison: She was the woman who lived in the great big house, and lived in the past, and still wore her old wedding dress, and everything was the same in the house, and it was dusty. Well, my father's family was kind of like that. They had once had glory, but they lost everything in the Depression. I remember he had a sister that lived in a big house, one of the biggest houses in town. It was a great big old Victorian house. We

were never allowed to go inside. We always had to stay outside. They would invite us in, but my father was ashamed of us and didn't want us to be around any of his family. He and my mother would go in, but we were never allowed to go in. And I never went in until I was grown, and then I didn't want to.

My mother's family were sharecroppers, so when my father would be in his drunken rages, he used to remind my mother that, "You were nothing but white trash. I pulled you out of the gutter, and look what I've given you." And my mother would say, "Yeah, look. I now have a tin roof." But my father and his family were always kind of looking down on where my mother and her family came from, because they were so much poorer.

The interesting thing is that my father's family had nothing either. So I grew up with all this craziness, dysfunction, and not a clear identity, and lots and lots of family secrets. There's another whole story about all that. But I wanted to get away from all of it as quickly as I could.

I tried to figure out at a very early age how I could get out of doing hard labor. Because I was little. I was the smallest male; I was very frail; I was always sick. I remember everybody used to say, "Oh, he'll never live until he's grown; he's so frail. He's the runt of the litter." I used to think, I'm going to die. Everybody tells me I'm going to, so I must.

But when I was about twelve years old, I came in one day and I said to my mother, I said, "I am not going to work in the fields any more." She said, "Well, what do you suppose you're going to do?" I had always said I wanted to be a doctor. There's another reason behind that, that the person I'm named after was the physician that delivered me. He had performed an abortion on my mother and it didn't work, so I was born as a result of it. So my mother named me after him.

The Civil Rights Movement actually grew up out of all this, because this doctor was murdered by his black mistress, and it became a big scandal. Books were written about it. Talk about true southern soap operas, I mean, this was good stuff. People wouldn't believe it, it was all so bizarre.

Seeking Higher Education

Hospital Work

Morrison: But anyway, I decided that I wanted to work in the hospital, and I was twelve years old, thirteen. The laws had just been passed where you had to be a certain age, I think, to work. But it just so happened that there was this woman that had grown up with my mother who was the administrator at the local hospital. It was just a tiny little community hospital, Suwannee County Hospital, and I was the only one in the family born in a hospital. It was the first Hill-Burton hospital built in the United States. They closed it and tore it down just a couple of years ago. But I was one of the first babies born in this first Hill-Burton hospital.

> So anyway, I went to the hospital one day, and I asked to see the administrator, Mrs. Johnson. And everybody was like, Why does this kid want to see her? I told them, "Tell her who I am and she'll see me." And she did, because she had grown up with my mother, and I think she understood. I remember she had me come in her office, and she said, "Now, what can I do for you?" I said, "You know my family circumstances. I have to work. I will do anything in this hospital that has to be done, but I have to have a job." She said, "Okay, I'll find something."

So I started working in the hospital, mopping the floors and carrying out the trash and the laundry. I did that for a couple of years, and then I became an orderly.

I was trying to figure out while I was in high school, Now, how am I going to get to college? One of the things that I've certainly been very proud of is that I am definitely a product of the Great Society. I was one of these people who grew up thinking LBJ was probably my father. [laughter] I was so caught up in the whole mystique of the Kennedy-LBJ thing. I'm certainly a product of the sixties--all that's being dismantled now--the opportunities for minorities or whatever.

What a lot of people forget was that it was also the first time that there were opportunities for poor white people in the South. There were a lot of people that managed to get pulled along in that, and I was one of those people. I know of a lot of other poor white people that were, too. It scares me to think that if I were in the same situation back there now, I probably wouldn't have those opportunities.

Educational Opportunities in the 1960s

Hughes: What specifically did you do?

Morrison: Oh, all of a sudden there were opportunities for education. In the sixties, just so many things opened up all of a sudden. Because I read a lot, and by that time we had a television, I was able to follow what was happening in Vietnam, and I was really beginning to see what was happening in the world around me. So I was aware. I remember my mother saying to me, "Well, if you're going to college, how do you think you're going to go to college?" I was like, "There are ways. There are definitely ways."

> I applied for a nursing scholarship, and got it. That just absolutely amazed me. Looking back on it, I've often wondered, growing up the way we did, why we were not on welfare. But my mother didn't believe in welfare, and we never took charity, ever. We just always managed to get by. Now, I believe very much in the social programs that we have in this country. I think they certainly need to be reformed somewhat. But I've often marveled at the fact that we grew up with none of that. We didn't go to doctors; we didn't have insurance. If you fell, if you hurt yourself, if you cut yourself, my mother patched it up and that was it. We didn't see dentists.

So by the time I was a teenager, I began to realize that there were opportunities, I just had to figure out how to get to them. So because I'd worked in a small hospital by that time for several years, I got to know all the doctors; I knew all the nurses. I was a pretty hard-working person, so they all knew my circumstances and they were all trying to push me along.

I think people generally wanted me to go to medical school, but one of the people that I admired most was a nurse. She was the one who told me that there were certainly ways to get scholarships, so I did.

Nursing Student

Morrison: I went to Florida Community College in Jacksonville, Florida [1969-1971]. It was an associate degree in nursing program. I was the youngest person that they'd ever taken in; I was only seventeen at the time.

- Hughes: Were you still holding on to your idea of being a physician?
- Morrison: Oh, yes, definitely, I was.
- Hughes: This was a stepping stone toward your goal?
- Morrison: Yes. Let's face it, although I think that I was fairly bright, considering what I'd come from, my experiences were very narrow. I saw nursing as a stepping stone that I'd be able to use. "Oh, I'll get an associate degree in nursing; I can make \$10,000 a year working as a nurse. I'll be able to put myself through medical school." So that's what I set out to do.

I worked my way through school. I always worked full-time, because my scholarship didn't cover anything but tuition. But immediately I began to start having different feelings about health care and about nursing itself, and found that I really liked nursing. I resented it, because I was almost ashamed or embarrassed that I wanted to be a nurse. But also, this was the height of the Vietnam War, and that's the point in history when the most men entered nursing. I went into nursing at that time.

Hughes: Why was there an influx during the war?

- Morrison: Because the economy was expanding, health care was expanding rapidly, and because the military was full of medics.
- Hughes: I see, who had had a taste of medicine.
- Morrison: Who had had a taste, and people coming from poor backgrounds as well, who wanted to make something of themselves. Most schools of nursing created programs for all these military corpsmen to be able to go right through nursing programs very quickly. So I went through nursing school with all the other men in my class who were corpsmen, and I was the youngest person. Even the females were all older than me. At that point in time, the percentage of men in nursing reached almost 5 percent, I think. That's the highest it's ever been. It's down now to about 2 percent. So that's basically how I got into it.

Working and Studying

Morrison: Then I worked in Jacksonville, Florida, at a public hospital [University Hospital] for a couple of years [1971-1972]. I started going back to school. I went to Jacksonville University for a semester and found I couldn't afford it. It was a private school. So then this friend of mine that I had gone to nursing school with moved to Miami, and a new state university had just opened there. It was called Florida International University. Their nursing program was what was called at the time a two plus two, meaning if you already had an R.N. license, that you could go back to school for two more years and get your bachelor's degree.

> So I enrolled and moved to Miami. I started working for the University of Miami and for the county hospital there, Jackson Memorial Hospital, and worked my way through school. Got my bachelor's degree [1974], still thinking that, Oh, well, maybe I'll do medicine. But I found that at each step, I let medicine go a little bit more. I had had more time to work with doctors, and I realized that if I wanted to make money, that medicine had to be the way to go, because I was never going to make it in nursing.

> I really liked what I was doing. I liked the contact with patients; I liked taking care of people. Let's face it, with an ACA [adult child of an alcoholic] background, I've always had this need to take care of other people. Psychiatrists have a field day with stuff like that. You look at nurses and social workers, and you'll find that a lot of us come from backgrounds like that.

But I was beginning to let the idea of medicine go a little bit at that point and was beginning to think, "Oh, whatever; This [nursing] is interesting." But I decided at that point, If I'm not going to go to medical school, being just a staff nurse is not really what I want to do. Although I like it, I'm never really going to make a living, and also, I don't like working nights and weekends. So I decided, Well, the thing for me to do is to look at the administration track.

Graduate School

Morrison: So I enrolled in graduate school [Florida International University] to get what would now be called a combination of an M.B.A. [master's degree in business administration] and an M.P.H. [master's degree in public health]. In the late sixties and early seventies, M.P.H.'s almost completely disappeared. They came up with all these different degrees that were like master's of science in whatever.

Well, I got one that was a master of science in health care administration [1976], but it was basically heavy public health. But half of it was through the School of Business, which I truly enjoyed because it was a totally different focus for me. I had to change my whole orientation, and that's where I really began to start looking at the issues in health care and nursing, and began to think of it more in terms of business, and what was needed to make all these systems work.

It was probably around that time that I also began to come together with my philosophy, my whole approach to health care, what it should be if we can have the ideal, because the sixties were certainly a very idealistic time. Although I think Nixon was president by then, I had probably become even more liberal than I ever was before. I remember at that point preaching to everybody that I thought health care was a right, and the richest country in the world should be able to provide health care to all of its citizens. So that's where I was at that point.

But I finished this degree, and then I got the opportunity to teach nursing. I really excelled at that, and I loved doing it, but the dean of the program told me, "Well, you have a master's degree, but it's not in nursing. So in order to continue teaching, you really do need to go back and get a master's degree in nursing." So I did.

I enrolled in a double degree program, and I got a master's degree in nursing and a master's degree in adult education [University of Miami, 1979]. So all of a sudden in 1979, I found myself with three master's degrees and thinking, I've been going to school nonstop for nine years, so what am I going to do with my life now? I thought, well, it is time to go back and get a doctorate, and I knew that sooner or later I would.

The whole idea of medicine had kind of drifted away from me at that point. But still it was back there. I was still young enough, I thought, Oh, I could do medicine if I want to, but I don't really want to. I like what I'm doing now.

By 1979, with all the things that were happening in the country, and particularly in Miami--I don't know if you remember the Anita Bryant years?

Hughes: Oh, yes.

Morrison: A lot of people, a lot of gay people in particular, have certainly seen her as a villain, and I think perhaps at the time I did too. But I've always been very grateful to Anita Bryant.

Hughes: Now, explain to me why.

- Morrison: Anita Bryant opened my eyes and forced me out of a closet. Because of what Anita Bryant did, I was forced to take a stand. It was very painful, it was very difficult, and I risked losing absolutely everything to do it. But I did it.
- Hughes: So you hadn't been "out" to the people that you were working with?
- Morrison: Oh, no. In those days, it was only in places like New York and San Francisco where people actually openly lived "out". I was one of those people; I was probably about half in, half out. My close friends were all gay, my social relationships, but certainly at work, no. Not at school. I was afraid of discrimination. And certainly, looking back on it, I'm sure that most people knew. But also, up until the eighties, there really wasn't that much an awareness of gay people. People didn't really think that much about it. Some people might say, "Hmm, don't you think maybe he's gay?" But most people just didn't have a concept of it.

I was literally forced to fling open that closet door, and I'm glad that I did. I certainly didn't become radical with it. I did get involved. A turning point for me was that I participated in a march in Miami, and I carried a sign that said, "Human rights are absolute." It wound up on the evening news. So of course, there were some problems at school all of a sudden, because one of the things coming up out of this was, "Do we want homosexuals teaching our children?" And at school, somebody said, "You're going to have a lot of explaining to do, because we're not supposed to be involved in stuff like this."

I remember getting very indignant, and made an appointment to go see the dean, who was actually a pretty liberal person and pretty much agreed. She thought it was kind of humorous, I think. I said, "I realize that some people here are upset with what I'm doing. I just want to make it clear. I'm not saying that I'm gay, and I'm not saying that I'm not. But I'm saying that I have a right to free speech in this country, and I do believe in what I was doing. I was carrying a sign that said, `Human rights are absolute,' and I firmly believe that. And if this school wants to do anything about it, I'll go get an attorney." She just kind of laughed and said, "Don't worry about it. Go ahead and do whatever you feel you need to do."

One of my best friends from years before in Jacksonville was from San Francisco. I had been coming out here usually once or twice a year to visit Ken Barton. I knew by 1972 that I wanted to live in San Francisco, but just thought the town was a little too fast. It was a little bit too much of a big city for me still. Miami wasn't at that point quite as cosmopolitan as it is today. I finally came to grips with who I was; I came out; I was open about it, and I decided, I can go to San Francisco; there's nothing to hold me back.

Moving to San Francisco, 1980

Morrison: One day I realized, I've been making all these excuses for years about moving to San Francisco one day, and all of a sudden, it was just like, I can do it now. Everything careerwise came to a halt. I had taken a job as director of nursing of a small hospital [Dodge Memorial Hospital, Miami, 1979]; I was still teaching part-time [assistant professor, Miami-Dade Community College, School of Nursing, Miami, 1976-1979]. I had run my course in Miami and realized that I was ready to go on and do other things.

> My mother still lived way up in the Panhandle, almost 500 miles away, but it was easier to get to her. I could get in the car and be there in a day. And I'd always said that as long as my mother was alive, that I would never leave the state. But I finally decided, I need to do this for a while. So I decided I would come out here for just a year. I think we all do, when we come here.

Hughes: And were you pretty assured of getting a job in nursing?

Morrison: Yes. I came out here, I was working part-time through registry, to get settled. But I'd already checked around and knew that there were jobs available. Well, I was a clinical nurse specialist because I had a master's in nursing, and I'd had a background in mental health, and I had done emergency room nursing as well as a lot of floor nursing in medical/surgical areas. So I had a pretty rounded background in terms of educational credentials. <u>Clinical Nurse Specialist, Department of Psychiatry and</u> Forensic Services, San Francisco General Hospital

Morrison: I got hired [1980] at San Francisco General [SFGH] as a clinical nurse specialist in the Department of Psychiatry and Forensic Services. The forensic services at San Francisco General is on the top floor, the seventh floor of the hospital. Now, there's a locked unit up there. It's a jail ward. I mean, it's likemaximum security; it's like going into a prison. You go through sealed doors and there are guards, and all of this. Well, at that time it was one unit; now it's two. Half of the unit was med[ical]-surg[ical] patients, and the other half were psych patients.

> These were all people from the jails that were somewhere in the legal process, that either wound up having some medical problem or were shot or stabbed or whatever, and they wound up there; or they had some emotional breakdown in jail and were unfit to be there, so they were there [at SFGH]. So I was hired as clinical nurse specialist, and I also worked as a therapist.

I was responsible for staff education for med-surg and for psych, but then I also had my own patient load and I saw patients, and wrote the reports for the courts for them. I liked that a lot. It was very exciting to me. But that's probably one of the few things in my career that I truly burned out on very quickly, and it wasn't because of the people that I worked with. I found that the mental health system in California had been totally over-hyped, because by the time I got here, the whole community movement was dead. Mental health services in San Francisco were not that great. They might have been better than they were in other parts of the country, but it certainly was no model.

And I found that the legal system working in forensic services was just so horrendous, it was just unbelievable.

Hughes: You mean the complexity of it?

Morrison: The complexity. I was in a position where I was the patient advocate, and I saw how people inadvertently could get into the legal system. It absolutely surprised me at how the whole system, the courts all the way down, once a person found themselves in our facility, if they were on 7D at San Francisco General, there was just an assumption that, for whatever reason, these people were guilty--of something anyway. I remember saying to one of the sheriff's deputies, "This person is really sick, and he didn't commit a crime." And I remember him standing there saying, "They all play to people like you because you're such a pussyfoot anyway, but the bottom line is, they've got to be guilty of something. They wouldn't be here if they weren't." And that said it all. That was exactly the attitude all the way up and down the line.

And every now and then, you'd see somebody that inadvertently got into the system and couldn't get out. They didn't have the money; they didn't have the connections, or whatever. And I saw how unfair it was, and how people were mistreated, so that also helped shape my philosophy. I really began to think a lot about how I would do things if I were ever in a situation where I could do them.

II THE AIDS EPIDEMIC

Learning of a New Disease

- Morrison: I truly was fed up with the Department of Psychiatry and with the legal system at that point and took a leave of absence for the summer [1981], went back home and spent some time with my mother, which I'm very glad that I did because she died within a year. I decided that I was going to leave forensic psychiatry. I wanted to go back into straight general medicalsurgical nursing.
- Hughes: Now, you took this leave of absence with the idea of going back to San Francisco?
- Morrison: Oh, yes. I just needed to take some time off, so I took the summer off and traveled around the country and spent some time with my mother.

I had already begun to hear about AIDS at this point, because this was 1981, and we were all certainly beginning to hear about it. It was right around that time, I had managed to connect somehow with Angie Lewis.¹ I can't even remember how, because I was clinical faculty for the School of Nursing at UCSF, and Angie and I had gotten involved in some nursing activity.

It was also about this time that I met Helen Schietinger.² Helen Schietinger is the person who got me involved in HIV work. At that point, Helen was already the head nurse of the

² See Schietinger's oral history in this series.

¹ See Lewis's oral history in this series.

AIDS clinic [Kaposi's Sarcoma Clinic] at UCSF.¹ I attended a two-day sexuality workshop, to which the Department of Public Health tacked her on as the last speaker. And almost everybody had left. I was absolutely fascinated, because I'd already been hearing and reading about it.

I had a roommate [Wayne Czito] that was my best friend, somebody that I knew in Miami. After I moved out here, he moved out here, and we had a very large two-bedroom apartment further up the street here. I remember one day saying to him, because Wayne was a party animal and was always out, "You know, there's a problem going on here. This is going to change our lives completely. We all need to start taking personal responsibility and looking at this." And it was so funny, because I remember Wayne turned to me and he said, "Oh, god, here you go again. You are the most prepared person in the world. You're the person who predicts earthquakes, hurricanes, disasters; you're always prepared for all of them. You never go out without an umbrella. You're always predicting doom and gloom and the end of the world, and here you go again." And I was like, "No, no, Wayne, this is going to change our lives." And he was going, [casually] "Oh, okay."

Hughes: Where had you gotten your information?

- Morrison: The first time I ever heard of AIDS, I think, was the first articles in the <u>San Francisco Chronicle</u>. There were little blips about it on TV, this strange illness that was in gays. That immediately got my attention. And somewhere along the line, it must have been a few months after that, the <u>Chronicle</u> or something did on the Sunday feature a story about this strange illness. I remember I was just reading through it, and I was like, This is an issue; this is really going to become a problem now.
- Hughes: But you weren't hearing about the epidemic through the gay community?
- Morrison: The gay community was in complete denial about it at that point. Yes, there was some talk about it; people generally just kind of giggled about it. It was like, "Oh, it won't happen to me. That happens to other people." Let's face it, a lot of denial, but also, we were a lot younger, all of us--and young people tend to think that they're going to live forever,

¹ Schietinger became nurse administrator of the clinic in January 1982.

and that they can control all of this stuff. Certainly I think that was the general attitude.

I turned thirty right around that time, so I was beginning to feel like I should be finally growing up a little bit and becoming more mature. It's interesting how everything shifted for me at that point. I realized that I wanted to make a change in my career. I was fed up with health care and with nursing and with the whole bureaucracy, and my thought at that point was, I don't give a damn if I don't ever work in health care again. I'm so sick of it, it's so controlling, so hierarchical, so traditional, so white-male dominated, and it's one point of view, and patients have no rights, and the rest of us are just peons. We're literally nothing but glorified slaves.

I was beginning to think, I'm going to transition myself out of health care altogether. The first thing I'm going to do is I'm going to get out of this forensic psych stuff that I'm doing, and I'm going to get back into general med-surg for a while. So I'd asked for a transfer, and they were giving it to me. We were in the process. I took a leave of absence about this time.

Just before I took this leave of absence was when I heard Helen Schietinger speak. I went up to her afterwards and I was so impressed with it, I said, "I really feel like I should be doing something." She said, "Well, there are lots of things you can do. There is an organization called the Shanti Project." So she told me about it. So I immediately signed up with Shanti and went into one of their trainings.

- Hughes: When was this?
- Morrison: Well, I actually wasn't able to get into Shanti's training right away, because I didn't do the training until December of '82.

Early Cases

Morrison: As I was doing that, AIDS, predominantly PCP, cases were popping up all over the place. I was transitioning out of the Department of Psychiatry. I was doing some work in AIDS before I actually took the Shanti training, because I was already getting called downstairs to the critical care units because they had these patients. The nursing staff and the medical staff had never seen anything like it. I mean, not only the physical, but the emotional aspects.

At that point, hardly any of us had ever seen a young male, twenty-four, twenty-eight, thirty years old, on a ventilator, alert. Nobody had ever seen an alert person on a ventilator before, because by the time people got on ventilators, they were out of it, pretty much.

- Hughes: These were largely Pneumocystis patients?
- Morrison: I think *Pneumocystis*, yes. And the critical care units at San Francisco General were just filling up with these patients. There were times when the medical ICU [intensive care unit] was almost all *Pneumocystis* carinii pneumonia.
- Hughes: When did you start seeing those cases?
- Morrison: The latter part of '81. By early '82, we were seeing two, three, four at any given time. By the end of '82, there were times when in the medical ICU, all the beds were taken up with *Pneumocystis*.

At that point, I started counting AIDS cases. UC had shifted everything over to San Francisco General. UCSF is Parnassus on the hill, that's Heaven and God over there, and anything that is controversial, dirty, or beneath them goes to San Francisco General. So I think there was the attitude, "Oh, okay, this is not something we want up here. It's dirty; we're not going to have to deal with it anyway; send it to General."

- Hughes: Despite the fact that the KS Clinic had been going for some time by then.
- Morrison: Exactly. Of course, Paul Volberding¹ came on the scene, and Paul was certainly junior in that hierarchy too. He, along with a lot of us, wound up doing some of the things that we did because nobody else wanted to do them, and they didn't think anything was going to come of it [the epidemic] anyway. So we all just kind of inherited this disease, because nobody else wanted to deal with it.
- Hughes: Now, they didn't think anything was going to come of it because they thought that the epidemic would be ephemeral?

¹ See Volberding's oral history in the AIDS physicians series.

- Morrison: It's interesting looking back at that point, how people felt about all of it. I think definitely the basic overlay was denial at every level. The other thing was, Well, okay, this epidemic is something, although it sounds really terrible, it's probably going to come and go very quickly, it's certainly not going to change the status quo on how we deal with things. Another thing is, an older man said to me, "It's so distasteful. It's just not something that nice people really want to be involved in." I think that statement said a lot.
- Hughes: Was he a health care professional?
- Morrison: Yes, he was. I think he was an administrator. I can't remember who this was.

At this point, I was going to meetings--I was already getting really involved, and started consulting with the staff in the critical care units on these patients. I would spend time with the patients, but I would also work with the nursing staff and with the physicians that were willing to hear what we had to say about how to deal with these patients.

The Need to Know about Gay Culture

- Hughes: You were transitioning from forensic medicine. Why would they consult with you?
- Morrison: Because of all the denial around this, the AIDS epidemic quickly flung open a lot of doors. San Francisco had a reputation of being the gay mecca, but, in health care, we knew very little about gay lifestyle. And San Francisco General, being a public hospital, was certainly used to serving the underserved of the community. But no hospital really made any arrangements to deal with gay people. A gay person's identity was not dealt with in the private sector or the public. And certainly, at San Francisco General, there was not a sensitivity to gay issues, although a large number of the staff were gay. People could be out, but there wasn't a sensitivity generally to gay issues or that there might be a need to look at these issues in relationship to an individual's care: how it would impact him.

I remember saying to people then, "This is just like trying to care for a Filipino or somebody from the West Indies or from China. You've got a whole cultural system here that you need to be aware of, because you're not just treating or caring for a person. You've got to look at the person for where they're coming from, and in order to do that, you have to have some understanding."

Hughes: So they recognized that you knew this culture?

- Morrison: Yes.
- Hughes: There was some recognition that this dimension had to be treated, or was it the other way around? You told them that it was essential to know about gay culture?
- Morrison: It was a little bit of both. I didn't have to be very pushy at that point. I became pushy later on. I was fairly well known in the hospital, and somehow, probably quite by accident, somebody found out that I was working with people in the community with AIDS.
- Hughes: Because you were doing Shanti already?
- Morrison: I had to wait to get into the Shanti training, but I already had begun to look around at what was going on in the community.
- Hughes: Were you also known as a gay man? Was that part of it too?
- Morrison: Yes, it was. At that time, nobody thought of anybody else but white gay men that this was happening to. What happened was that the providers in that particular institutional setting were just absolutely aghast. I mean, here they had these patients that were horribly sick, very young, they were dying. Not only were they dying, but they were demanding as hell, and they were alert. They were ordering people around, and they were refusing treatment; they were pulling out tubes. Because the system had no sensitivity to them. They [the providers] were throwing up their hands. They didn't know what to do. "We can't deal with this."

Then on top of it, you've got this young guy as a patient, and some other guy comes in and says that he's his lover or his partner or whatever, and is demanding rights. "We don't give these people rights; they don't have any rights."

So what I found myself doing was basically trying to sensitize people, the nursing staff, as to, "Okay, now this is the relationship, and this is how you need to treat this patient so that he isn't upset; relate to him this way." I would spend time with the patients, and I would say things to them like, "Don't fight the nurses and the doctors. Try to talk to them, try to explain to them, try to ride it out. We will be here; we'll advocate for you."

At that point in time, literally, the average gay man in San Francisco would not have been caught dead at San Francisco General. It was the county hospital. San Francisco does have the largest gay ghetto, so you do have all the social and economic layers that go with it. But by and large, I think the community was identified as being pretty much middle class. So most everybody did have their own health care insurance.

Hughes: Then why did they end up at San Francisco General?

Morrison: Because the first cases that we saw really were the people at the fringe of the gay community, to some extent. Or maybe not even so much fringe. Some of the first cases I saw were people that certainly were involved in a lot of different things-drugs, bathhouses. Their lifestyle had already contributed to a weakened immune system, so that by the time this thing hit them, they were already vulnerable. And also because people didn't seek treatment early enough. By the time we got them, they were literally at death's door.

> In 1982, at San Francisco General, like 85 percent of the patients that came in with a diagnosis of *Pneumocystis* died on that admission. Because we just did not have the sophistication to treat it and to deal with all of the other psychosocial issues that literally confronted the whole system at once, and the system couldn't handle it. I mean, staff were refusing to care for patients. There was discrimination, but a lot of it really wasn't discrimination: it was a fear. All of a sudden, there were all these issues that health care providers, the people who should know, we'd never dealt with.

> At this point in my career, I was not comfortable discussing sex. My education had never included anything much about sexuality. There was no understanding or sensitivity to the fact that one needs to even consider sexuality in relationship to illness. Now we realize how totally ridiculous that was. The system still hasn't changed a lot, though. There's an awareness, but the system still hasn't changed.

> But in 1982, it was rigid, and there was all this denial. It was like the door to darkness had been opened, and all of the taboos were out--sex, death, homosexuality, drug use. Things that people had never heard discussed openly before, and all of a sudden it was all being discussed, and it was out there.

- Hughes: One reason that you were called in was because you as a gay man "should" be able to deal with these issues?
- Morrison: Yes. I had a background as a therapist; initially what I was called down to do was to deal with the patients. "We've got these irate patients who are out of control, who won't listen to us, who are not conforming; they're not cooperating. See what you can do with them." And I found that I actually had a lot of success with them. But I also saw the need then to work with the providers as well, but did that a little bit more subtly. I certainly didn't say, "Well, I'm going down because I've got to help the staff learn how to deal with this patient." I was very careful not to say that at that point.
- Hughes: Now, Cliff, were you having any trouble with what role you were playing? There are two roles that you've mentioned: the role of you as a professional health care provider, and also the role of you as a gay man. It seems that both those roles are in demand.
- Morrison: Yes.
- Hughes: I suspect that you had never before had to synchronize those two roles.
- Morrison: No, I never had. I guess because of the crisis of the situation that really did not present a lot of problems for me personally. I mean, there were problems there, just not so much for me, personally. I remember thinking, Oh, god, it's one thing being at San Francisco General and being out, and people knowing that you're gay; but all of a sudden taking on this whole identity.

Maryanne McGuire and the Concept of an Inpatient AIDS Unit

Morrison: Well, it was early into the epidemic; I'd been doing this for a while, and I was transferring downstairs to the medical division. I ran into the director of nursing, Maryanne McGuire, in the cafeteria one day in fall, 1982. She said, "Oh, I'm really glad to hear that you're transferring downstairs. By the way, a number of the staff have commented about your work with these patients upstairs. I'd like to talk to you some more about it."

> While we were eating I said to her, "You know, this is just getting completely out of control here. We're getting more and

more of these patients. Today there are twelve people in this hospital with *Pneumocystis* or KS [Kaposi's sarcoma]. And look at the situation: we've got patients who can't come out of their rooms because they're totally isolated; people won't clean their rooms; stuff is left outside the doors; their food is left cold at the door. The critical care units can't handle them. They might be able to treat the physical aspect, but nobody's addressing all these other problems. We need to have some sort of coordination."

She said, "Well, what would you propose?" I said, "Well, I don't really know, but it's obvious we need to have something." And she said, "Well, why don't you think about it? Come back to me next week, and we'll make a proposal to administration."

Talk about things that people have never wanted to cover before, because this is truly politics of San Francisco, the Department of Public Health and everything else. I have written so many different things about this particular piece of history, and every time that I've ever done it, or in an interview, I've always said that this person--her name is Maryanne McGuire, Maryanne McGuire Hickey now--if there was any one individual in the institution that I think truly understood and truly felt that we could do something, it was her. And she's never gotten any credit for it, because of a lot of politics at the institution and in the San Francisco Department of Public Health.

Also within a year and a half after that, San Francisco General almost closed when Dianne Feinstein was mayor. They [Department of Public Health] publicly said that they fired all the administration at San Francisco General, but they didn't. They just kind of reshuffled them and put them all over the place. Well, Maryanne was one of these people that got blamed for a lot of stuff, and they shuffled her off down to the Department of Public Health. So nobody wanted to hear that she contributed to anything, so it just got looked over, got really pushed down.

Hughes: Why do you think she was receptive?

Morrison: She was the person who hired me at San Francisco General, and I've known Maryanne for a number of years, and she's an extremely complex person. But I think above all, she is truly a patient advocate. I really and truly believe that Maryanne McGuire is a nurse. There's just no other way to put it. She's got that feeling for people, that compassion. And it's interesting, because she's Catholic and I'm Catholic. I don't know that much about her personal life, but I certainly had always made an assumption that her politics was probably fairly conservative. She had probably never been around gay people that much before until she found herself at San Francisco General and being director of nursing. And she's not an older person; she's only a few years older than me.

Yet, I knew from the time that she interviewed me that she was not homophobic. I remember we were talking about this problem with gay patients, and I was wondering to myself, Why is she being so open to this? She said that an orderly or something at San Francisco General was sick with this. She knew this person. I don't really remember the details of this, so it might not have been somebody that was an employee of the hospital; it might have been somebody she knew. But I remember she looked at me, and she had tears in her eyes. She said, "This is the most terrible thing that any of us have ever seen, and nobody deserves to be treated the way that these patients are being treated. If there's anything that we can do, then we have an obligation to do it."

As history has been written along the way, it's always come out that it was Paul Volberding or somebody else at some other level that came up with the idea of an inpatient AIDS unit, but actually it was Maryanne. And I was very much against it at that point. In 1982, the whole discussion around units at that point was isolation: how to keep these patients away, how to protect staff, how to basically put them in the back of the hospital as far away from everything as possible. That was the discussion.

Hughes: And yet, from what you're saying, that was not her idea at all.

Morrison: Oh, not at all, not at all. She really wanted to see these patients receive humane, compassionate treatment and care. At the same time, she was very much concerned about how the staff was dealing with this, and she wanted to make sure that there were systems in place for the staff to be able to care for these patients. I mean, she was very progressive in her thinking on this.

> So I went back to her a couple of days later and essentially said, "Okay, I've thought about it; I think this is what we should do. Since I'm transferring down here anyway, why don't you let me basically become"--AIDS wasn't even a word that was being used yet--"the clinical coordinator." As a clinical nurse specialist, there's this role that's kind of merged--clinical, educational, coordination, et cetera. And I said, "And I'll work to coordinate the care." Because at that

point, we were averaging six to eight patients a day. That was manageable, I thought.

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Morrison: Maryanne went to the hospital administrator [Geoff Lang]. There had already been discussions at a high level about, "We've got a problem. What are we going to do?" She essentially said, "Cliff Morrison is a clinical nurse specialist, and he basically has a proposal. We'd like to move forward with this." And essentially, I think, everybody was just kind of like relieved. Okay, something needs to be done. Pressure was already coming to bear from the community: "What are you going to do?" The media was beginning to really pick up on all of this stuff. Everybody realized that we were heading towards a crisis, but nobody knew what it was, and nobody wanted to deal with it.

> So anybody that would step forward at that point and take any sort of leadership role was appreciated. And thank god we were all allowed to do it, but we were all allowed to do it for all the wrong reasons. I certainly don't want to speak for Paul Volberding or some of the other people, but I am almost positive that he found himself in essentially the same situation that I was in; it's just that he was at a different level. His physician colleagues didn't really want to deal with this. He kind of inherited it, and everybody was like, "Hm, nothing's going to come of this anyway. Nobody wants to deal with it. Let Paul do it."

Of course, after Paul made something of it and people began to see that it really was a major issue and that careers were going to be built on it, then everybody else started jumping on the bandwagon. Well, that was the same with me. My close friends and colleagues at San Francisco General and everywhere else were saying to me, "Cliff, you are an absolute fool to do what you're doing. You're going to ruin your career completely. Nobody is ever going to hire you. You're going to wind up with a title that's associated with this disease that nobody wants to deal with. You're never going to have a job in health care again, because everything will be out."

I remember my response at the time was, "I don't care. I'm burned out on health care anyway. I want out of it. This might be my only opportunity to make any sort of contribution towards health care." That's where I was coming from. Actually, my thinking was probably about an inch-wide [laughter]--not very broad at that point. I certainly wasn't thinking about models, or the San Francisco model, or how it was going to influence the rest of the world, or whatever. I was just thinking of how I would feel if I had this disease. I was very concerned about friends that I knew.

Like a lot of people, I read enough early on that I almost knew from the beginning who among my friends were going to have AIDS, although it didn't have a name at the time. I said to a couple of close friends, "My roommate Wayne is my best friend in the world, and I love him dearly. But I know that he's probably going to wind up with this disease, and I want to make sure that if he does, him or any of my other friends, that I'll be able to be there for them and to provide them with what they really need." So that was where I was coming from.

Later on, I started doing a lot of work with Elisabeth Kübler-Ross. Elisabeth was always very fond of saying that there are no accidents in life, that everything has a purpose and meaning. I used to hear her say that and thought, Oh, yeah, she's off on one of her tangents again. But certainly as I've gotten older and I've looked back on it, it seemed like there were just too many coincidences, too many things came together at a given point in time.

Early Participants

Paul Volberding and Mervyn Silverman

Morrison:

I've often said the whole history of the epidemic would be totally different if a handful of people had not been where they were at the time that the epidemic broke in San Francisco. It would have been totally different if Paul Volberding wasn't where he was, if it had been somebody else. It would have been another story entirely if Merv Silverman had not been director of public health in San Francisco. Here's a man who's probably one of the most open and sensitive people I have ever worked with. I have more respect for him than probably anybody I've ever worked with, so I'm always able to say I'm not physicianbashing, because there's nobody I love more than Merv Silverman. The man's made a lot of mistakes, but I tell you, if he had not been director of health when the epidemic broke in San Francisco, the whole history in this city would have been totally different, believe me. He advocated for patients' rights from day one and didn't back away from it. So of course, it's easy for people now to look back and criticize some of the decisions he made, but nobody knew at the time what should be done.

Dianne Feinstein

Morrison: Also a factor was that Dianne Feinstein was mayor at the time. I'd done a lot of work with the union [Service Employee International Union (SEIU)]; I'd been on the negotiating team at San Francisco General, so I'd had an opportunity to meet her on several occasions. I always voted for her, but personally never liked her. She was a ball-busting woman. [laughter] And here I was, just coming to grips with a lot of these issues myself. And wow, here was this woman who's just--umph. I mean, men would grab themselves when she walked in a room.

> Well, of course, now I have a whole different appreciation for her, thank god. She learned a long time ago, and that's the reason why she's been a successful politician. How I would feel about her personally is totally irrelevant. I would vote for Dianne Feinstein for anything that she'd run for, because I think she did what a politician was supposed to do. She had enough background that she knew that AIDS was an issue. She met with Dr. Silverman and the administrator of the hospital and said, "What needs to be done? Tell me." So she opened the door. Let's face it, another mayor might have said, "Hey, we've got a \$70 million surplus, but we're certainly not going to spend any of it on this epidemic." Thank god that was the one time where there was a big budget surplus. There was money there; the Department of Health could do something with it.

Hughes: Yes, another factor that's very important.

Morrison: Let's face it, today that's certainly not the case.

David Werdegar

Morrison: So there were all these different things. We had people in place like Dr. David Werdegar, who later became Director of Health but at that time was I guess Associate Dean for Academic Affairs at San Francisco General or something like that, because all the medical staff from UCSF reported to him. He was in charge of all the training programs. Here was a man with a very strong public health background who believed very strongly in community involvement.

> So luckily, there were these people that were in place that didn't shy away from the issues of the epidemic.

Merle Sande

Hughes: What about Merle Sande?

Morrison: Dr. Sande was the Chief of Medicine, and still is.¹ I had actually just begun to work with him and just gotten a chance to know Dr. Sande at that point.

> Merle Sande is probably one of the most complex people that I've ever met. I have enormous respect and admiration for him. At the same time, he's not always the easiest person in the world to like. I actually have a different appreciation for him now than I did then. Dr. Sande is basically a conservative person. At the time, I knew nothing about him personally, other than that he was married and that he was a white male doctor who was very much into power and authority and wanted to control everything. People seemed to be pretty much afraid of him or intimidated by him, and when I met him, I could certainly understand why. My first thought was, Hmm, a good ole boy. He plays it to the hilt. I heard people describing him as being sexist, racist, homophobic, and if you weren't a doctor, you weren't anybody.

> So I became AIDS Clinical Coordinator on the inpatient side; Merle was Chief of Medicine, so I had to start working with him. It was bumpy at first, but I got along with him very well, and he seemed to get along with me. We always had all these meetings, and it was obvious that he was not only fascinated by it, he was aghast at some of it.

Hughes: You mean the disease itself?

Morrison: The disease, and the issues that came up as a result of it. This was the first time for any of us that were gay that we sat in clinical discussions where gay sexuality and descriptions of sexual behavior were discussed, and people talked openly about anal intercourse. It was like every term that came up, everybody was like, [gasps loudly] "Oh my god! Can we talk about the issues?"

> There was a learning curve, and it's been interesting over the years to see how we've all changed. I'm sure that if you were to talk to Merle about me, he would probably say, "Yeah, Cliff has changed a lot over the years." Well, I've seen Merle

¹ In the summer of 1996, Sande moved to the University of Utah to become chairman of the Department of Medicine.

change a tremendous amount. Those first few years, I think he resented the epidemic--this is very subjective; this is my opinion. I'll mention to you an anecdote that got put into a couple of books that created some problems for me with him.

I would say that those first couple of years, I could work with him okay, but I didn't trust him. I felt like he was just barely tolerating us. I didn't feel that he had our interest at heart. He was certainly much more concerned with the medical aspects, and at that point didn't really seem to want to play a major leadership role. He wanted to know what was going on, but I don't think anybody at that point really saw that AIDS was going to change careers. Certainly I don't think Merle or Paul or anybody else was thinking that at that point.

- Hughes: So do you think he thought, "Thank god there's Cliff and his group to take care of this problem"?
- Morrison: Yes. "And I don't really want to have to deal with it anyway. I'm kind of responsible for it, but as long as I know what's going on and I don't have to do it, then fine, let them do it."
- Hughes: So Sande was not playing a direct role?
- Morrison: Not playing a direct role, yes. He was playing a direct role and an indirect role. By virtue of the fact that he was Chief of Medicine, he was involved. In the beginning, I think that he kind of resented it. I think he began to get a little bit more interested in it, and was actually fascinated by some of the titillating details of it, like a lot of people were.

Selma Dritz

Morrison: And then there were some people who dealt with it just absolutely wonderfully. Selma Dritz was one of those people. Thank god this woman was where she was at. Well, she is just one of the most wonderful people in the world, and I love the fact that Lily Tomlin got to play her in <u>And the Band Played</u> <u>On</u>. Although Selma Dritz was much older, Lily Tomlin could capture her eccentricities. I think almost all of us were rather eccentric people. Maryanne McGuire was; Merv Silverman was. Paul Volberding to a less extent, but I think he's become a little more eccentric as he's gotten older. And I think Merle Sande is certainly a very eccentric person.

Selma opened the door for a lot of people, because here was this little old lady who looked like she could be anybody's grandmother, or the bag lady down the street, and she would stand up and go into these frank discussions, citing everything, and talking about anal intercourse and fisting and all this. She could discuss all this stuff without a smile, just deadpan and serious. I was in love with her. I was in total awe of her. And yet, it was obvious that she had an enormous amount of sensitivity and feeling about it. She also knew that this was kind of like her swan song; that she was getting ready to retire. So she was on top of everything. People respected her and listened to her. I think because of the way she approached things, it opened doors and smoothed things for a lot of us who came afterwards. The fact that somebody at her level was able to discuss these things without blushing, without batting an eye, made her a perfect role model.

Selma left it all far too early [late 1984]. She certainly wasn't a casualty; she retired. But certainly she was one of the first people that was involved early on to move away from it, and she was missed before she was gone.

- Hughes: Aside from her role as--
- Morrison: Epidemiologist, you mean?
- Hughes: --a provider of an explicit view of what was going on in San Francisco, not pulling any punches, was she providing your group at San Francisco General with a broader perspective on what was happening in the city as a whole?
- Morrison: Oh, yes.
- Hughes: And on what the CDC [Centers for Disease Control] was reporting on a national scale?
- Morrison: Oh, yes.

The Kaposi's Sarcoma Study Group

Morrison: Almost immediately, a couple of different meetings sprung up. We would have monthly meetings either at San Francisco General or on campus at UC, or every couple of weeks; I can't remember now how often they were. And people from the health department-

Hughes: The KS Study Group?

Morrison: Yes. And we'd all come together, and everybody would be discussing what was going on. Marcus Conant usually handled it over there at UCSF; Merle or Paul would handle it over at San Francisco General. Selma was always at all of those.

> We also started a coordinating group through the Department of Public Health, and we always met downtown in Merv Silverman's conference room. I was a much more formal player in that group. The other one, because it was more a medical model, I went, I got to hear everything, I got to even have some input, but essentially, the nursing piece of it really wasn't important. They would turn to me when issues would come up about gay sensitivity, things like that.

- Hughes: You mean, the physicians turned to you?
- Morrison: Yes. It was almost completely composed of physicians. There were only a few nurses in the room, and a few nonphysicians. But that group that met at San Francisco General and UC was almost exclusively physician. The nurses involved were infection control people; Angie Lewis was involved, I was involved, Gayling Gee, and early on Helen Schietinger, but then she was out of that picture pretty quickly.

More on Merle Sande

Morrison: I went back to San Francisco General for a year and a half [January 1994 to May 1995]. I was director of clinical services for the EPI [Epidemiology Prevention Intervention] Center, which does all the counseling and testing for HIV, and it's responsible for hospital infection control, and stuff like that. So I had an opportunity to do some work with Merle Sande again, and actually got to see him and Julie Gerberding socially a few times. He's gotten older, and his relationship with Julie has softened him in some ways, made him much more open. A lot of that roughness was gone.

> Miguel, my partner, and I had dinner with him and Dr. Gerberding, and I remember him talking about his childhood, and the difficulties of growing up. Miguel is not in health care, and he's always in awe of anybody that's a doctor. I had told him, "We're going to meet, and we'll have drinks with them." He had already met Dr. Gerberding and thought she was absolutely charming. I said, "Now, you might have difficulty

with Dr. Sande, so just prepare yourself. I don't want to influence how you might perceive him."

I remember we walked away from that, and Miguel was like, "He was charming! He was one of the most charming people I've ever met! What were you warning me about?" And I said, "He's just totally different. Ten years ago, I would have never seen him sit down over dinner with two gay men and discuss lifestyles and how we grew up, and to see him laugh and all of that." I've certainly seen him soften a lot.

I think that the HIV epidemic profoundly changed Merle professionally, personally, as with all of us, none of us intending it to happen. Whereas myself, Gayling Gee, Helen Schietinger, and the other nurses, we created roles for ourselves and pushed ourselves into them and created things. Paul Volberding did that to some extent too. Merle Sande kind of inherited some of it, and in the beginning was reluctant and didn't really know what to do with it. But then, within a short period of time, he realized that he did have a role, and then took it seriously.

I think that Merle's actually handled it very well over the last few years. There's certainly resentment at a lot of different levels about his role, because Merle is a very strong person, and let's face it, strong people are always resented. But as time went on, I think he learned a lot about himself, and about other people, and about lifestyles, and I think that he became much more sensitive. He's a much different person today as a result of it. It's encouraging to me. But at the same time, I think, Well, was he as bad as we all thought he was in 1982 and 1983?

I found myself in the middle of all of this, and that was very traumatic, and certainly for everybody, because we were dealing with an unknown. See, we didn't know how the disease was transmitted. We knew that it was an infectious disease and it wasn't spread through the air, because everybody would be getting it. So we knew a lot about it. But still, there was all this stigma attached to it.

Community Outreach

Morrison: Here was a county hospital that apparently had a reputation for working with different groups in the community, but San Francisco General didn't. I think most public hospitals didn't at that point in time.

- Hughes: You mean in the sense of pulling in community agencies and community volunteers?
- Morrison: Definitely. Yes, San Francisco General was just barely scratching the surface with that at the time. There was the Hospital Community Advisory Group, and things like that. There was certainly more of an awareness in dealing with the African-American community, because they had been so vocal during the sixties, and I think that that was one of the first pieces that got put in place.
- Hughes: Does UCSF use community outreach as an indication that the university is a community service organization?
- Morrison: Yes.
- Hughes: Was that an appropriate thing to do?
- Morrison: Oh, I think it's very much an appropriate thing. I think a lot of institutions have done it for the wrong reasons, but I'm glad that they've done it.
- Hughes: I phrased that wrong; of course it's appropriate for the university to have community outreach. But did the administration also have the attitude, "Well, these people have set up a system of community AIDS care which plays into our Public Relations venture"? I suppose it's unfair for me to suggest that that was an unjust claim, because you were part of the university, and why shouldn't the university claim it?
- Morrison: Yes, at that point, '82, '83, so many things were happening at such a fast rate, and they were all happening at the same time. Looking back on it, literally it felt like being in the eye of a hurricane. Things were just spinning so quickly around me, and around all of us, and none of us knew what was happening or what was going to happen.

The Media

Morrison: Once the media latched onto it, and I think really began to dictate it, we just began to respond to the crises. We manipulated the media; the media manipulated us. We learned a lot about it. I think a lot of us learned how to do public speaking, how to deal with the media. I certainly learned a lot of things about all of those issues, as well as things about myself. I learned early on that to be able to do what I needed to do, and to work with the people that I needed to work with, I needed to stay away from the media as much as I could.

Those of us in health care talk about change more than probably any other professional group, but we are the least accepting of change. We want everything to stay the same, because we're comfortable with it. We'd been very comfortable with this hierarchical role, with everything being traditionally structured so that you've got a top, you've got a middle, and you've got a bottom. Everybody knows their role, and everybody knows the pecking order and who to report to or whatever. It makes it real clear and real easy; it's almost like the military in that respect. Then you have something like this epidemic that comes along and shakes it all up. And none of this fit. It was just all so different. So everybody was like, "Huh."

Constance Wofsy

Morrison: You mentioned [off tape] that you had talked with Connie Wofsy.¹ There are people that I look back on and I realize that they were wonderful role models for me at the time and have truly been like angels. I always wear an angel on my lapel because of that.

> Connie Wofsy was the only woman physician that was really involved clinically speaking; Selma was at the health department. Connie Wofsy was always such a voice of reason. I think that a lot of it had to do perhaps with some of her own issues as a woman, having to deal with medicine, and the fact that she was a little bit more sensitive to it.

Hughes: You're talking about the human side of what was going on?

Morrison: The human side of it, and how she handled herself, how she dealt with things. I looked up to her, as a lot of us did. When we opened 5B, I had a great relationship with all the physicians coming to the unit, but when she appeared, whatever I was doing, I would drop and go with her, because I wanted to

¹ See Wofsy's oral history in the AIDS physicians series. Connie Wofsy died in 1996.

be with her when she'd make rounds or when she would come on the ward with her [medical] team.

Hughes: What did you observe that she did that maybe others didn't?

Morrison: Oh, she was one of the first that was a true teacher with the medical students and the residents. She'd come into the unit, and they'd be following behind her. She could present things objectively, but she was also very emphatic about, "This is our role; we have to have compassion; we've got to put our feelings [prejudices] aside; we can't judge people." She was probably the first physician that I heard say some of those things, and that certainly stood out for me.

> But she was kind of a lone voice at that point among the physicians. I think because of the relationships within the university and academia and all of this, there was always constant jockeying. Everybody was going in their own little sphere. You've got the doctors at the top, but even within that group, you've got the white male doctors--Marcus Conant, Merle, Paul Volberding, Donald Abrams--all of this group. And they're swirling up here and competing with each other and jockeying to get the most attention or whatever. Then you've got somebody like Connie Wofsy, who is doing her thing and is in there and is certainly a part of it, but because she is a woman, she has a somewhat different perspective and different expectations--

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Morrison: --than some of the other people that I was dealing with had. So yes, maybe because she was a woman, maybe because she knew what discrimination was, she knew how difficult it was for her to compete within that system, and as it still is. I don't think things have changed a lot. There are more women, but they still have to deal with those issues.

Gay Physicians

Hughes: Two of the physicians that you named are gay. And one could surmise that they would be the ones who would be more apt to pick up on the humanistic side of medicine, because these were suffering people from a community with which they identified. Morrison: It's an interesting point. After all these meetings, everybody would go back to their corners or whatever, and we'd talk within our little groups. Most of the people I was working with at that time were gay, and we would talk about how the doctors were dealing with this. Well, those gay doctors were not out at that time. I think a lot of people suspicioned. We knew that they were gay.

> I've had a clinical faculty appointment at UC almost since I've been in the city, for fifteen years at least. One of the things about UC that absolutely amazes me is that you go over to that campus, and almost nobody is admittedly gay. Now, it's moved forward a lot over the last few years, and there's certainly a lot more sensitivity and awareness. But nobody over there is really out. That's not a part of yourself, because UCSF is so competitive. Go to San Francisco General, and it's pretty easy to see who the gay doctors are, because they kind of stand out. Although the General is part of UC, it's a different setting altogether.

> Marcus Conant to me was always a fascinating person, because I think everybody knew that Marcus was gay, but I don't think at that point I ever heard him say it.

Hughes: It wasn't a discussion point.

Morrison: Exactly. It was not something that polite people discussed. And since there, quote, were no gay doctors [at UCSF], then it just was never mentioned.

> Donald Abrams was probably the most open at that point, because he was our age, he was younger, and I think Donald was certainly a lot more out there. And I respected him for that, because I think he also made it easier for the rest of us in some ways. But at the same time, it made it very difficult for him, because he wound up having to compete, and he's still paying the price for all of that. I think that in some respects, he's been held back, and probably feels that. I don't know; I never discussed it with him.

Hughes: Held back because of his homosexuality?

Morrison: Yes. I think Donald Abrams should be a lot further along. He's made enormous contributions at UC, and in this community, and in this city, and I don't feel that he's gotten the kind of recognition that he should. I want to be careful in saying that it's because he's an openly gay man, because I think a lot of it has to do with the competitiveness of physicians in academia and in the UC system. I've often wondered if he were married with six kids at home, if that would have made any difference.

Hughes: The first AIDS clinic was at UCSF.

Morrison: Yes, the KS [Kaposi's Sarcoma] Clinic.

- Hughes: Which was largely Conant's creation. There are complex reasons why AIDS activities transferred to San Francisco General. Was one of the reasons the fact that the director of the KS Clinic was a gay man?
- Morrison: I think it has everything to do with it. Again, it's important for you to understand that this is my perception of what was going on at the time. However accurate or inaccurate it was, it was what I saw and what I felt. I think Marcus Conant probably found himself in one of the most uncomfortable and difficult situations of his career. Here he was making enormous contributions and getting the kind of recognition that he deserved. I've never had these discussions with Marcus, so I don't really know how he feels about it, but I certainly remember watching him and noticing how he handled things. He was able to go into all of these discussions, never refer to himself as a gay man, always talk about the gay lifestyle in the third person, so to speak. And he was always able to do it without ever flinching or feeling embarrassed.

I think that a lot of it had to do with the attitudes at the time and within the UC system. Parnassus¹ has always had a reputation for being fairly homophobic, although I think there are probably more gay people working on Parnassus than there are at San Francisco General, and that's saying a lot. It's just that once you're over there, you downplay it. I used to really just be amazed over in the School of Nursing and other locations. You're surrounded by gay people. You don't mention it; you don't talk about it; this is not a part of our personalities or our lives that are ever discussed here. This is academia; it's too competitive. You don't want anybody to have an angle on you, and that's an angle. At the same time, I think a lot of people know. But again, because UC is what it is and Parnassus is where it is--it's no accident it's on a hill.

Hughes: [laughs] Good point.

¹ Parnassus Avenue and Parnassus Hill are the location of UCSF.

Morrison: It's like, polite people don't have these kinds of discussions. I never talked to Marcus about it; it would be interesting to do so now, because I think that he could probably laugh about a lot of it. Although he certainly never showed it, he must have gone through a lot of personal agony. And I think he did pay a price. He got recognition within the university, and certainly locally, statewide, and nationally, and a lot of what he put in place is certainly the backbone of what became the San Francisco model. So I think his place in history is certainly secure.

> But my take on it is that Marcus probably paid a price within the system for it, that although I think he handled it beautifully, he was certainly low-key about it, but at the same time making sure the information was out there. I think in some respects, it probably doomed him within that system. I don't know what he could have aspired to within that system, but I think certainly because of that, his fate was pretty much sealed, because he was a gay man. And I think that he's also gotten more comfortable about it now as he's gotten older. Again, I don't know.

Marcus and I are from the same area. He grew up in Jacksonville [Florida], and of course, I grew up just eightyfive miles away in the middle of nowhere.

Ward 5B, the Inpatient AIDS Unit

Geoff Lang, Hospital Administrator

- Hughes: Let's go back to the process of setting up 5B. I think we left off with your approaching the administrator, who was Geoff Lang?
- Morrison: Geoff Lang was the hospital administrator at that time.

Hughes: You came with an idea.

Morrison: Yes. So many things have happened over time; a few years ago I would have never said things like this. I personally liked Geoff Lang. I thought he was a really nice man. He was a disaster as a hospital administrator. He was weak. He always wanted to test the political waters before making a decision on anything. In fact, he wouldn't make decisions. And he hated confrontation. How in the hell could somebody be CEO of a hospital and hate confrontation?

He was certainly very nice to me, so I have to be careful that my criticism is balanced. But also, I think when you're doing an oral history, it's important to be as honest as possible. It's part of who I am and what I am that I'm able to see both sides and try to understand why people reacted and dealt with things the way that they did at the time. When I say things about any of these individuals, it's not so much that I dislike them or that I'm attacking them or that I'm criticizing them. It's just, this is what I saw.

Also, you would hear criticisms about me from other people. Certainly I think that around 1983, particularly by 1984, a lot of people saw me as an opportunist. They thought that I pushed myself onto the scene and shoved myself down everybody's throat, and I did, because I had to; I had no other choice. But again, I think it's one of the things that makes it all so fascinating. You never really get the straight of anything-interesting choice of words [laughter]--because there are so many different factors involved, and you're dealing with very complex individuals.

Geoff Lang probably was the weakest link in the fence at that point. He didn't really want to do too much. He was uncomfortable with the whole thing, and had the least to say, and probably would have done nothing if it hadn't been for Merv Silverman and the mayor. It was essentially the two of them that said, "Okay, all right, let's move forward with this."

Now, I wasn't at the meeting that Maryanne McGuire had with Geoff Lang about, "This is what we should do," but she took the concept to him. My speculation is that he was his usual self, "Hmm, well, hmm, okay, but keep it low key. Don't cause any problems. I'm under pressure from downtown to do something, so you all go ahead and do it. Keep it as together as possible, and don't make any waves, and I don't really want to know the details. Don't embarrass me." I think that's pretty much where he was coming from at that point.

I don't mean to be critical, because he was dealing with something he'd never dealt with before. No other hospital administrator had ever been confronted with this situation. I think he knew zilch about the gay lifestyle. He was constantly under fire from everything downtown. Plus he had all these overbearing physicians on his butt, primarily Merle Sande. Merle would not hesitate to walk right down to his office and tell him, "This is what I want and I want it done now." Hughes: And Geoff had to do something?

Morrison: I knew him the least of any of these other characters. In my years of association with San Francisco General, the hospital's had at least ten CEOs. Geoff Lang was probably one of the longest, and had only just become really settled at San Francisco General when all this happened. The city has never really wanted a strong administrator at San Francisco General. You don't want somebody who's truly a leader there. Because of the politics of this city, the power has to be downtown. And a truly dynamic CEO at San Francisco General could overshadow politicians, and that would never work.

> In fact, after Geoff Lang departed, we had a series of acting administrators, one of whom would have been the ideal person for CEO, but he was never even offered the job. The reason why was because he was far too dynamic; he was far too much of a leader, and he would have been telling the health commission and the Department of Public Health what should be done, and that's not going to happen in this city. That's just the politics of the situation.

Silverman's Role

Hughes: Now, did Silverman have any role in 5B?

Morrison: He did, very much. He came to these meetings, and I went and met with him. When it was announced that I was the AIDS coordinator and that we were going to develop a program, and at this point we didn't really know what kind of a program we were going to develop, he met with me. The first time I actually sat down with him, I remember thinking to myself, Where is this man coming from? I could kind of get a read on everybody else. But with Merv, I was kind of like, Is he for real? Is he putting this on? Is he trying to manipulate me, or what? He just came across as being too understanding, too sensitive, and I thought, Nobody else around here is, so why is he?

> It was at that point that I actually became fascinated by Merv and began to do a little informal research about, where did this man come from? What was his background? Just before that time, I had had the opportunity to do some work with his wife, who was finishing her doctorate and was up on one of our psych units doing her internship. I absolutely adore Deborah Silverman.

You've interviewed Dr. Silverman, haven't you?

Hughes: Yes.¹

Morrison: Well, one of the people that probably has one of the most different angles on all of it is Deborah Silverman. She's lived through every minute of it. She's one of the most wonderfully warm, compassionate human beings I've ever known. She is Mother Earth. One of the things that warmed me to Dr. Silverman very early on was that he was such a family man, and still is. Actually, I think he's more so now than he was then. I love seeing the two of them together. I don't see them as much as I used to, but I do consider them both two of my best friends. There's something, being a gay man, that I find extremely reassuring about seeing a heterosexual couple that's been married for thirty years that are loving and affectionate. When they're together, you can see this love between them. can see her when she looks at him, and I'm like, "Oh!" It gives me a tingle. It's exciting, and it's wonderful, and I'm fascinated by it. I've never seen that before, so yes, they certainly have become very special people to me.

> Deborah's one of these wives that has always tried to stay in the background. She would never do anything to overshadow her husband. He'd be the first to tell you that his wife is everything. She makes it all possible for him. But she probably went through more torment and torture than he did, because she's the one who worried about it; he didn't.

Hughes: Now, you're thinking particularly of the bathhouse episode?

Morrison: Oh, all of it. I think even today, with his role at AmFAR [American Foundation for AIDS Research] and all the things that he's still involved in. He said to me once in the six years [1986-1992] that we worked together on the Robert Wood Johnson Foundation project [AIDS Health Services Program, Institute for Health Policy Studies, UCSF], that she was his conscience; she was his best friend. She was the person who could walk in and say, "You're wrong, Merv." And he'd listen.

> It's what Hillary Clinton is being criticized for today. [laughs] Society can't make up its mind, what is the role of the woman. Do we want her to be the happy little housewife who stands back and supports her man? But if you're going to support your man, you don't tell anybody.

¹ See Silverman's oral history in the AIDS physicians series.

Hughes: So what role did Dr. Silverman play in setting it up?

Morrison: The mayor had said to him, "We've got this budget surplus. You let me know what needs to be done for AIDS, you ensure that it gets done, and I'll ensure that you get the money for it." So the first time I met with him about this, he said to me, "Okay, we need to get some cost estimates together; we need to plan all this stuff."

> There had already been a discussion of an AIDS unit, but we'd pretty much ruled it out, and I was very much against the whole idea of an AIDS unit. I did not want it in any way. I thought, with an average of six to eight patients a day, we can handle it where these patients are in different wards. We don't have to have a specialized unit.

Arguments Against Creation of an AIDS Unit

- Hughes: One of the arguments I've heard against creating 5B was that it might become a leper colony.
- Morrison: Oh, yes.
- Hughes: Was that a concern of yours?
- Morrison: Oh, it was my major concern. I remember telling close friendsconfidentially, of course--"I've taken this job because I'm going to ensure that we never have an AIDS unit at San Francisco General. Because the history of public institutions trying to do anything like this, it will be an absolute debacle; it would be the worst thing in the world that could ever happen to our community, let alone to health care." So here I was in the midst of all of this, and being as low key as I could be. I was all over the place, and I was involved in a lot of things. I was very much aware of my role and my position. I certainly have an understanding of diplomacy and politics.

And in those days, I was certainly walking on eggshells, and there were a lot of people who did not like me at all: what I stood for, what I was doing. I even had colleagues, nurses, professional friends, that were upset with me. They felt like, "You, of all people. Why would you even validate any of this? This is all stuff that none of us wants to have to deal with anyway, and you're validating it; you're working essentially with the enemy; you're giving them information about our lifestyle that we don't want them to have. Why are you doing this? It's going to ruin your reputation; your career is going to be ruined." So I was catching it from a lot of different directions.

I've thought a lot over the years about how I dealt with that. And I guess there was a lot of denial for myself as well. I just kind of went through it. I've always been a very goal-directed person, and when I see that I have a goal at the end, then I just go forward. I'm aware of what's going on around me, and I'll do what I have to because I learned survival skills along the way, but I essentially stay focused on what I'm going to do until I get it done. That certainly is what saved me, because I don't think that my personality is that strong. I want to be loved; I want people to like me; I don't like criticism, and I heard a lot of it. I knew that there was an enormous amount of criticism against me.

Participation of Community Groups

Morrison: At the same time, I was getting an enormous amount of support from the community, and I was bringing in these gay groups to work in the hospital. That was the first time I actually had to meet with Geoff Lang around stuff like that, because he was very uncomfortable with the gay issues. Staff were complaining.

Hughes: Now, when you say groups, you mean Shanti [Project]?

Morrison: Shanti in the beginning, and some of these informal groups that were springing up in the community to deal with the different [AIDS] issues that were coming up. He was like, "Well, is it necessary to bring <u>those</u> people into the hospital? Do you realize how upsetting it is to everyone?" And I was like, "Well, this is a public hospital, and my take on public health and the role of this institution is that it should be working with the community. You've done it with other groups, not that well, but you've done it. I think now is the time to do it with this group. You've got a lot of work to do; you've got a lot of P.R. to do, because the gay community does not trust this facility, and never will."

More on Silverman

Personal Characteristics

- Morrison: I never really thought the gay community would ever come to support San Francisco General the way that it did. But then again, it was all these things that were in place that all kind of fell together, and the fact that Dr. Silverman was so popular. He was probably the most high-profile, popular director of health the city has ever had.
- Hughes: You're talking about the opinion of the city as a whole, not just the gay community.
- Morrison: Yes. He's always had this charisma that comes across on film and on video, and a great speaking voice, and he's always had the silver hair and the beard--
- Hughes: Yes, very photogenic.
- Morrison: Merv Silverman was only forty years old at that time.

The Bathhouse Issue

- Hughes: Yet, he, like you, certainly suffered. I'm thinking particularly of the dissension over his perceived tardiness in closing the baths.
- Morrison: Well, a lot of people criticized him. He's the only doctor that I know of, or anybody that was at that high level, who came very close to his career being over because of the politics of AIDS. I mean, his career was almost ruined. But Merv Silverman, because he has strong support behind him and because he's got these personality strengths, was able to bounce back from it and, like a lot of us, turned lemons into lemonade. He made it work for him.

I know Merv Silverman very well, and we've had lots of talks, and for six years we worked together very closely. There were times when it would just be the two of us in the office, so we could sit and brainstorm and talk about things and deal with the politics of the situation. So I got to know Merv, I think, better than anybody else that I worked with through that period. He was a very aware person and not afraid to take chances, which I think is the thing that really set him apart from everybody else. I think it's a real strength, but, and I think even he would say this, it is probably also one of his weaknesses. Whereas everybody else was being very, very cautious, Merv was not afraid of the issues. From day one, Merv didn't bat an eye about it. From what I know and from talks with Deborah, they essentially arrived in San Francisco like a couple of hippies. Merv had a ponytail; she wore sandals until a few years ago. They truly looked like a hippie couple, raising their little kids on a commune or something.

Both of them having grown up in the [Washington] D.C. area I think grew up with an understanding of politics, plus they'd had other experiences--the Peace Corps. Deborah had put her career on hold at that point and was basically raising a family. They had a wonderful life in Wichita. She was not the one who really wanted to come to San Francisco; he wanted this. But then I think she immediately fell into it.

- Hughes: You were talking about the health department's role in 5B. My impression of Dr. Silverman is that he is a man that sees things complexly.
- Morrison: Yes.

Hughes: That there's seldom a simple answer.

Morrison: Yes. I think throughout his career, Merv has never been afraid to make a decision, and I don't think he was afraid to make a decision in the bathhouse crisis. It's probably--I wouldn't say the only time--but the time that he hesitated the most. He did everything he could to get consensus. Talk about an education in civics and politics for me: that was, oh, boy. I'm so glad that I got through that whole bathhouse debacle without being scalded. There were a number of things that I managed to get through in those days without being tainted at all, and that was one of them.

Morrison's Refusal to be Involved in Bathhouse Closure

Morrison: Everybody tried to get me involved in that issue, even Merv. I remember running into Merv one day, and he was like, "We're having this hearing, and, Cliff, it's really, really important for you to be there." "Actually, I don't think I can make it, Merv," and he was like, "But it's so important. You're a leader in the gay community, whether you like it or not." Let's face it, I was an informal leader. And he said, "People know who you are, and it's important that they see that you support this." I said, "I'm not sure that I do support it. And on the other hand, it's a no-win situation for me, and quite honestly, I think it's a no-win situation for almost all of you involved in it.

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- Morrison: So I purposely stayed away from it. Randy Shilts tried to get me involved in it; Merv tried to get me involved in it; oh, a couple of other people--names escape me as time goes on. "You have a responsibility. We need you to speak up about this." And I said, "I'm not. And I refuse to."
- Hughes: Did you have a stand?
- Morrison: I did. I thought the bathhouses should have been closed. It was obvious; we had enough information at the time. I essentially agreed with Randy Shilts; I just didn't agree with his message completely.

Silverman's Tension with Randy Shilts

Morrison: Talk about times where you find yourself in really strange situations: I had a great relationship with Randy Shilts and a great relationship with Merv Silverman, and of course, the two of them hated each other. Hate might be a strong word, but Randy had absolutely no love for Merv Silverman at all.

> Randy let me read the manuscript¹ before publication; he let a number of people look at it. I got back to him and said, "You cannot end this book the way that you're ending it." He painted Merv Silverman as pretty much a dark figure throughout the whole thing. I had said to Randy all along, "Merv is not that way." And I said to him, "Randy, I won't have anything to do with this book at all. I don't want my name anywhere on it. I know how you feel about Merv Silverman, and perhaps some of it is justified. But we have to remember what was going on at the time. And I know why you're upset with him." Let's face it: Merv barred him from Grove Street [administrative offices

¹ Randy Shilts. <u>And the Band Played On: Politics, People, and the</u> <u>AIDS Epidemic</u>. New York: Penguin Books, 1988.

for the Department of Public Health]. Randy couldn't go in there and interview anybody because Randy was constantly attacking Merv.

Randy could be like an old dog with a bone. He was a fascinating person, but when he was on to something, he wouldn't let go of it. He was a journalist in the true sense of the word. So there was certainly a lot of feeling. And here I found myself suddenly between the two of them, and two people that I really felt very strongly for, in different ways. Later on, when Merv and I worked together, we had a chance to talk about it a lot, because it kept coming up. As Merv and I worked together, Randy would resurface at times, and he would always say things to me, "Well, I know how you feel about Merv, and Merv is your good friend." I was constantly having to deal with that, as all of us were.

Then there was this awful confrontation that occurred at one of the earlier International AIDS Conferences in a session, where Merv and Randy wound up yelling at each other. Maybe it was Stockholm, I can't remember. It was just a few months before <u>And the Band Played On</u> came out. Merv was on a panel and Randy was in the audience, and they wound up having a shouting match. It was the usual stuff. And in our line of work, you have to support one person. So I wound up hurting myself, I think, a lot throughout, because of the way I've handled or not handled a lot of the politics of the situation. I understood the politics, but I realized that my role was different. So to keep myself from losing my focus, I just did not involve myself with a lot of these other political issues that I saw would do nothing but destroy me.

I've always been very careful. It's one of the reasons why now, I'm really not that visible in the gay community and in the politics of the gay community, because I never sided with either of the political clubs in the city, never really got involved in their politics, and never received any recognition from them either. I've received recognition from everything else. I have a box full of awards over there from just about everything. But it's because I didn't play politics within the gay community.

I didn't play politics, period. It's not that I thought that I was so important or so much better than anybody else, but I felt like I had this little piece that I had to focus on, and I knew what I could do, and I just didn't feel that I could do it in the political arena. I also saw what happened to everybody that stepped into it. So it was a difficult situation.

More on Ward 5B

Creation

Morrison: After a few months of my trying to coordinate care, work with the patients, and deal with the staff, and all of the issues that were going on--I found myself working fifteen, sixteen, seventeen hours a day, and it was just getting ridiculous. I was working on weekends, and it was consuming me. I began to see that this was not going to work.

> So I began to think about, How are we going to deal with this? The numbers of AIDS patients were increasing dramatically. So then I went back to Maryanne McGuire. She'd been saying, "I think we really need this AIDS unit," and I'd been protesting. I went back and I said, "I think you're right now. I think the time is right. But I think that we need to do it for all the right reasons, and not the wrong reasons. And let's do it with a pure nursing model." And she was like, "That's exactly what I want."

> So then, everything really began to take on a completely different spin. Once that decision was made that we were going to go forward with the unit, we didn't discuss it a lot. The media wasn't interested; nobody said anything to the media about it. Randy Shilts and I had been talking for quite some time. He was aware of it, but even he wasn't that interested in it at the time. He used to come out and spend time with me at the hospital, going to see patients and things. I learned a lot about Randy personally, where he was coming from, his own fears, fears that I think a lot of us had at the time.

The Media's Role

[Interview 2: January 19, 1996] ##

Personal Impact

Morrison: I want to amplify some of the things that we've talked about, and how I think that they're important. I can't emphasize too much that it's very subjective; it's how I remember things. And one of the things that I've certainly learned is that not everybody remembers things the way that I remember them. I'm glad that I do have some of this stuff written down, because then it is a good point of reference.

Something that is important is the role of the media, which I think is another whole story in itself, but particularly in how it related to me. I said to you that the media is such a big piece, and it changes so many things. I had never been in the eye of the media. Oh, a couple of times I might have been interviewed before this [the epidemic], because of other things that I had done, but certainly I had never been the feature, and my picture had never appeared in a paper.

When I got involved in AIDS, I wasn't thinking, Oh, well, there are going to be stories written about what I'm doing, or that I'll be interviewed by someone, or that my picture will be in the paper. When that started happening, it was almost like a bomb explosion. If you've ever seen the pictures of the atomic blast, it's like you have the blast, and then afterwards comes this sweeping wind, [whoosh]. It just rushes over everything. That's how I saw the whole media thing.

The first thing is that it's "Wow," and a feeling of, "Oh, my goodness, this really is important, and gee, I might be important too." So there is a real tendency to let one's ego build it up a little, and to think, "Oh, well, maybe I am more important than I really am." And I must admit that I certainly was very guilty of that, as a lot of us were.

One of the things that I learned very quickly, though, was how it got out of control. The media has a need to sensationalize, to put everything in sound bites. So it became extremely frustrating almost right away for me in dealing with the mass media to get the message across, because everything was in sound bites, and they weren't interested in hearing what the real issues were. They were interested in the sensational pieces. So oftentimes, you'd wind up being misquoted or taken out of context.

I found that extremely frustrating, but I put up with it for a while, because everybody kept saying, "Even if the media screws around with this stuff some, it's important that we get this message out. It's more important than the other issue." And I think part of that was true. The other part of it was that everybody was flattered by all this media attention. I know that I was.

One of the first things I noticed was that it created a lot of problems for me in my personal life and at work, because I had never thought before how your colleagues would relate to you once you had appeared on national television, or your picture was in the local paper, or something like that. And they relate to you differently. There's jealousy. There's like, "Why is he so important? What has he done that's so significant? You shouldn't be doing this; so-and-so should be doing this." Or whatever.

Hughes: Were these sentiments actually verbalized?

Morrison: Yes. And it comes from every level, every level within the bureaucracy, within the system, which coming from higher levels never bothered me, because I knew exactly where they were coming from. There was no problem for me there. I think where it hurt and where it bothered me the most and got my attention the quickest was with my colleagues, people that were at my level in the nursing staff. I saw that people were offended. They felt they'd been slighted in some way, and said, "Why are you getting this attention? It's taking away from our mission. You're spending more time playing to the media than you are doing your work. It's one thing if the mayor or the director of public health does it; it's another thing if you do it."

> And for a long time, I bargained with myself on it and rationalized saying, "It's important to do this." But I always had this feeling that I wasn't very comfortable with it and I didn't like the way the media was doing it.

> Then a couple of things made me decide that I wanted to back away from it. What it did in my personal life, I lost privacy. For a while I found it really difficult to be in the Castro, which was my neighborhood, because all of a sudden there was all this notoriety; I couldn't have a quiet dinner someplace without somebody coming up to me and complimenting me or castigating me or confronting me or something. I all of a sudden began to feel like, I can't get away from this stuff.

Hughes: Usually people that you had not previously known?

Morrison: Yes.

Hughes: They'd recognize your face.

Morrison: Yes, because all of a sudden, this stuff [AIDS and Ward 5B] was big news, and it was out there, and it was in the community. For about a year I had a sign on the inside of my door at home, so that when people came in, they'd see it. And the sign said, "AIDS is not spoken here." Because I needed a place where I did not have to deal with it. Maybe "AIDS is not spoken here" was not a fair slogan, because it had nothing to do with AIDS; it had everything to do with the politics around it, and I've always said that that was what tends to burn people out. It's not the issues of AIDS; it's the political issues of it.

But then I think also how things would get twisted. As long as the media is painting a good picture, it's fine. But the first hint of controversy, all of a sudden, you can turn from one day being a star into a villain very quickly. I think people who play with the media don't realize that they're playing with fire. Well, I was lucky, I was very lucky, because I saw all of a sudden one day after the "bombs" exploded and the flames were being fanned that I wasn't necessarily getting burned; I was getting singed a little around the edges. But there were people around me that were going up in smoke rapidly. I began to see what was happening to them, and it really dawned on me: This is going to happen to me if I keep playing with this. This is dangerous.

Hughes: So you withdrew?

Morrison: I made a conscious decision within about a year after being at that pinnacle with all that attention to start pulling away from it.

Hughes: When was that, Cliff?

Morrison: Oh, that was probably by mid-'84, because it created so many problems in my personal and in my professional life. I had a new boss [Judy Spinella] at San Francisco General by that time, and she was frightened by it. She was able to say, "You're getting too much attention. This is upsetting." Looking back on it, she tried to put it out there as, "It's not fair to your colleagues," but she was also saying, "It's not fair to me."

Hughes: This was a nursing administrator?

Morrison: Not Maryanne McGuire; it was the person that followed her.

The Gay Media

Hughes: How did coverage by the gay media go? Was there a different twist compared to the straight press?

Morrison: Well, because I had been working and planning and dealing with community groups for a while, certainly the first media was the local gay media. Somewhere in my boxes I have some of the first articles from the <u>Bay Area Reporter [BAR]</u>. An elderly man--I've tried to remember his name--who was a writer, started writing a book, and he interviewed me extensively. It was so colorful, and I thought it was just fascinating. So he started running excerpts of it in the <u>BAR</u>, and that's when I began to get attention from my gay friends and colleagues in the Castro.

Coverage of the Opening of Ward 5B

Morrison: Now, I think one of the reasons why all of this happened was because we were relatively low key, believe it or not. Nobody really wanted to deal with it. They [hospital administration] wanted somebody to handle it, and I did all of this stuff very quietly, without any thought of the <u>Chronicle</u> or local media or national media or anybody else really paying any attention to it, and didn't realize until everything was set for the day of the opening of the unit [summer 1983].

> Well, we wound up having to postpone the opening for a day, and that's when I began to realize that there was all this media attention. Now, I don't know if the media people at San Francisco General or UC are on your list of people to talk to, but there's only one that was there almost from the beginning. Her name is Gloria Rodriguez, and she was wonderful. I was very fortunate in that even before the big media blitz caught on, that I was being coached by a couple of really nice people in media relations, through the Department of Public Health and through the university: "This is how you answer questions. Be careful about what you say," that sort of thing. "These are people I think it's important for you to talk to." Because of the work that they did and the way that they helped me, I bonded with some of these people. Gloria is still there and I still consider her one of my closest friends. She has a lot of stories. [laughs]

> I remember Gloria telling me early on that, "This can blow up in your face. You really, really need to be very careful." You can hear that, but you don't necessarily know it's true.

The first real evidence of it was the bathhouse issue, where it blew up in everybody's face that was connected to it. And luckily, I got out unscathed. But around that time, there were other issues, because the media was running constant stories, so they always needed something new to sensationalize. So any of us that were involved were subject to, without ever being interviewed, being a focal point of something that was in a story. So I certainly began to realize, This could be detrimental to a lot of things and I don't want to have anything to do with it. So I consciously backed off at that point.

There were a number of training films being made at that time, and I thought, Okay, these are fine, because you have a chance to get your message across. And I thought, Okay, now is the time to start writing. The way to get this message across is to do it through the professional literature, not the mass media. So that's what I began to concentrate on.

The only part of the mass media that I really liked dealing with was radio, believe it or not, because radio was always much better at covering things. You would come on to a radio talk show, and there would be a chance to discuss something. There was something about radio, and it took me back to my early days as a child when we had nothing but radio and no television. To this day, if somebody says they want to interview me on radio, I'll jump at it, because it's fun.

Hughes: But you're not a television fan.

Not a television fan. I think I have some of the interviews Morrison: and stuff from television on video, and some of the controversies with some of the legal stuff that came up later -in 1984, a group of nurses at SFGH filed a complaint with the California Department of Health, stating that they were being forced, against their will, to care for patients with AIDS--and I handled it well. I think that I came across okay on film. But I wasn't comfortable with it, because I always felt that it was deceptive, and it scared me. It just wasn't me. There was a phoniness to it that I had difficulty with. It started bringing up for the first time that issue that's carried with me and a lot of other people all along--it's guilt. Guilt about being a gay man and about not having AIDS, survivor's guilt. All of a sudden, "Why is all this positive attention being focused on me? I'm not the issue. I shouldn't be the one being focused on; it's the story that's important."

> I began to see that some of my colleagues certainly lost that perspective. I understood it, because it came very close to happening to me. In fact, some people would tell you that it did. [laughs] But I thought that was certainly one of the biggest lessons for me.

- Hughes: You said, one of your motives was to get the information out. Do you think you went into an interview with, say, a <u>BAR</u> reporter with a different attitude than if it were a straight reporter from the [<u>San Francisco</u>] <u>Examiner</u>? Was that also a danger?
- Morrison: Yes, I think it was. I think I would have been intimidated by the media, period, but the first media that I did deal with was the *BAR* and some of the other gay papers, generally referred to as "the rags." Some of the reporting was not the best in the world, and there were always questions about their integrity.

However, I must say, my experiences were always wonderful. The *BAR* reporters that I dealt with, and there were probably three or four, were always wonderful, and they gave me an opportunity to present my side. I don't remember ever seeing anything in one of the gay community papers that I thought misrepresented me. Sometimes things would not be quite as I said, but I was always pretty much pleased by it.

So when the mass media came in, I thought, Oh, it's going to be like dealing with the local gay media. Well, it wasn't. I think after that, the gay media changed as well, because AIDS all of a sudden really sensationalized news coverage. It happened right around the time that 5B opened. I saw it at every level, and this is one of the things that really made me go, Whoa, this thing [AIDS in the media] is really big and getting out-of-control.

As we were preparing to open 5B, there was this media attention. SFGH and UCSF media relations came around and said, "So-and-so is coming, and people want to do this, and whatever," and I was like, What's the big deal here? There's really not a lot to see. It's a hospital unit that's about to be opened. Well, they built this thing up, and the day the unit opened, I think two of the three major television stations carried it as lead story. I think all three of them were there, or four of them, actually. And I thought, Oh, okay, that's interesting. It's local media attention.

I didn't realize until a couple of days later that it was national news, and all of a sudden I'm getting calls from friends and colleagues from around the country: "I saw you on the news. Oh, this is wonderful." And I was like, Whoa. Well, all of a sudden, this snowballed, just got so big that it was gone. It was out of everybody's control. It came to this point very quickly where sometimes I would spend half of my day not only with media people, but everybody wanted to come see the unit; everybody wanted to hear about it; everybody wanted to know how it came together.

There was a conscious decision made, Yes, it's important to spend some time with some of these media people, because this information needs to get out. But on the other hand, I knew what my priorities were, and in the beginning, it became really shaky, because I was flattered by the media attention. It's real easy to think of yourself as a star. [laughs] As I roll my eyes! At that point not realizing what would come after it, that everybody gets their fifteen minutes of fame; I had mine, thank god, and got out of it without being too blistered. But a lot of people didn't, so it certainly snowballed.

What happened after that was that it really became a situation of the tail wagging the dog. I think we literally lost control of what we were doing, because the media controlled it, and the media was dictating a lot of what was happening with all of us.

The San Francisco Model of AIDS Care

Hughes: Now, you mean "we" in terms of the staff of 5B, or in a more general sense?

Morrison: In a more general sense. I think locally, all of a sudden it was the San Francisco model. I remember being interviewed on television, and I'd never heard this term before. This reporter said to me, "Are you the architect of the San Francisco model?" And I'm like, "I don't know what you're talking about. Back up a little bit here. I worked on this piece [5B]; I coordinated with other people in the community." The media reported the San Francisco model as if this was a very deliberate thing, that we had thought about it; we'd all planned it; there had been all these meetings and all this wonderful cooperation. Some of that was true, but none of it happened that way.

> What happened was that there were all these pieces, and everybody was working on a piece here or there, and luckily, because there weren't so many of us, there was coordination and communication. That was the important piece. There was never a conscious decision, "We're going to sit down and develop a San Francisco model." I mean, that came out of the media from someplace.

- Hughes: There wasn't a conscious effort to develop a coordinated multidisciplinary approach?
- Morrison: You know, there was and there wasn't. Certainly when the media started reporting it that way, we started doing it that way. But it didn't necessarily start that way. We were doing it, but we were doing it and not really knowing we were doing it. Then you start reading these stories that sounded this was a master plan.
- Hughes: But you hadn't conceptualized it quite that way.
- Morrison: Yes, I said many times, we didn't start out thinking, Well, we're going to develop a San Francisco model. We were all responding to a crisis; different people doing different things: Gayling Gee working in the AIDS clinic with Paul Volberding; me working in inpatient and with community groups and with Merle Sande and with Shanti, and then trying to coordinate as best I could with Gayling and Paul, not always successfully because of the division with systems, because of UC and the Department of Public Health and all this stuff that was wrapped up in it. And then the AIDS planning group downtown with the Department of Public Health, and then dealing with Dr. Silverman's office, and the hospital administration, and all these other things.

All of us were communicating with each other, and I was fortunate in that I was communicating with almost all of these different people at some level.

Hughes: You were truly the AIDS clinical coordinator, weren't you?

Morrison: Yes. I was moving in and out.

Hughes: Were you more central than any other figure, Cliff?

Morrison: You know, it's interesting, I never thought of myself that way, but looking back on it, possibly. I want to be careful now that there's been fourteen years, and to look back on it historically, because of the criticism that's come along since then, I don't want to portray myself as being too important. I truly believe I played a significant role, and I'm very proud of the role that I played. There have been far too many stars in this epidemic, and I don't need to be a superstar in it any more. I finally came to the conclusion that it really didn't matter to me who knew what I did. In fact, I felt a lot of guilt around it, because the only thing that's really important to me at this point in my life is that I hope that people with HIV realize that I'm a strong advocate. And then there are all those people that I worked with and loved and cared for that are no longer here, and their memories are important to me. The whole idea of getting fame and notoriety as a result of it is very conflicting for me.

I'm not sure that I was a central figure. I think probably Paul Volberding really was the central figure, because of the emphasis and the importance of the medical model, and the fact that he was the doctor. I was probably moving in and out of circles perhaps a little bit more; I don't know. But the emphasis wasn't as much on me, so I could do that. I was a nurse. I realized the importance of what I was doing, without stepping on too many toes.

Hughes: Do you know who coined the term "San Francisco model"?

- Morrison: I think the first person was a female writer from one of the professional journals, that is probably in this bibliography. [tape interruption] Actually, Dr. Silverman very easily could have been the first person to use the term.
- Hughes: He certainly wrote a lot about the San Francisco model.
- Morrison: The first person could have very easily been Sari Staver, a reporter in San Francisco. She lives down in the Castro. She's a freelance writer, and she was writing for American Medical News. She's number twelve here. She's really wonderful. I run into her all the time now. It was probably her or [looking through papers] Traska, which is number sixteen here.

I have a feeling that whoever did it, and Merv is a very likely prospect, in talking about it, just inadvertently referred to it as "San Francisco model," and the media [snaps fingers], like they did everything in those days, snapped on it. "Ah, crystallize!" And great, a sound bite.

Paul Volberding

Hughes: Well, we were talking about the media, and certainly Paul becomes a media star, wouldn't you agree?

Morrison: Oh, yes.

Hughes: And what did that mean to what was going on?

Morrison: I think there was resentment towards him, not particularly in the beginning, but certainly I began to hear it from patients. Paul is a very endearing person. He's charismatic, and he's attractive, and people like him, and he's very personable. See, in the beginning, all of this was so small. Paul saw patients, and the patients really liked having a connection to him, that they could see him and they could talk to him.

> Of course, as things just mushroomed, not only was he constantly in the media, but everything got busier, and it got more complicated, and it got more bureaucratic almost overnight. So he was very quickly pulled away from the front lines of working directly with a lot of patients, and they resented it. I was in a position where I heard a lot of what they were saying, and there was some resentment. At the same time, I think what Paul was doing was so important that I think it overrode it.

- Hughes: Apparently, there was some sentiment on the staff too. Gayling said that there was a bit of angst when Paul wasn't a constant presence in the clinic.¹
- Morrison: Yes, there was. I agree with her completely.
- Hughes: You experienced the same thing on 5B?
- Yes. Gayling at that point was a university employee, and I Morrison: was Department of Public Health. Ten years later, we reversed roles completely, and she was the Department of Public Health and I was the university. She and I always liked each other and always got along well. I've always adored Gayling. People have challenged me on it: "What makes you say that?" There was an unconscious need to keep the two of us apart, because when 5B opened, there was this avalanche of media attention all of a sudden, and I and the nursing piece became so important because Ward 86 [the AIDS Clinic] was UC and it was pretty much doctorrun, and because everybody was afraid of inpatient. That was an untried area, and nobody really wanted to touch it, so everybody stood back, and that's the reason why the attention focused on me and nursing.

¹ See Gee's oral history in this series.

More on Ward 5B

Media Attention

Hughes:

People were scared because AIDS medicine itself was an unknown?

Morrison: It was an unknown, and also because it was truly the controversy of the time. An AIDS unit? Who in the world would want to have an AIDS unit? It's a leper colony. And then to turn around and do it for all the right reasons rather than the wrong reasons, and then to have it work, then all of a sudden everybody wanted a piece of it. See, in the beginning, they were all standing back. Everybody was like, "Okay, all right, let the sun shine in, and if it blows up, then you go up with it in flames." I think what nobody anticipated, and definitely I didn't, was how it was going to be received on the positive side. It was like overnight, it was this big instant sensation, and it was the thing to do, and a major piece of the San Francisco model, and how we were all so innovative and creative.

> Well, we were innovative, and we were creative, and that's great, but I think that's truly where the media kind of made this leap, and everything got muddled at that point. During that time, Gayling Gee got almost no attention at all. Now, I mean, Gayling was playing a role very similar to mine, but she was a university employee. Paul was her boss. I was getting a lot of attention and was constantly being interviewed, whereas when the media went over to 86, they didn't interview Gayling; they interviewed Paul. Almost no one else got interviewed over there. Occasionally Connie, occasionally Donald Abrams, but certainly the nursing staff hardly ever. Whereas when they would come to inpatient, it was me, or I would designate one of my staff to do the interview.

- Hughes: You're saying that some of the media attention was because of the actual structure? The fact that 5B was a nursing unit, and you were head of it.
- Morrison: Yes, the structure. It was the first time that something like that had happened certainly at San Francisco General, where something that had pretty much been identified as nursing got all of this positive attention. Nobody thought it was going to happen, and the only reason why it did happen and why nursing had that role was because everybody was afraid that it was tainted in the first place, so they didn't want to touch it.

People were saying, "Well, your career is made on this," and I was always very clear to say, "Hey, I had a pretty good career before this." I was doing okay. But certainly, that angst came in at that point, and it was certainly one of those things that did bother me. I used to often feel like Gayling got slighted during that period. She should have been receiving a lot of attention. But then later on, when she and I actually did a lot of work together and became very close friends years later, she said, "You know, at first it kind of bothered me, but like you, I very quickly saw that it was a double-edged sword."

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Morrison: I got out of that by the skin of my teeth.

The Primary Nursing Model

- Hughes: You mentioned your decision to set up 5B according to a nursing model. And I'd like to know what you mean by that, and was there any precedent, and what were the alternatives? How else could it have been approached?
- Morrison: There probably were other models, but never anything like this. I do feel that my contribution in nursing was this unit. I don't think that there had ever been anything in the history of nursing where nursing played such an important role, particularly in this community, and a pulling together of all these different models and concepts to come up with something. I used the term "nursing model" almost from the beginning, maybe even before "San Francisco model" came up, and probably because Dr. Silverman and I did a lot of talking. Merv might have heard me saying "nursing model," and then said "San Francisco model". Maybe it was something like that.

Hughes: Now, define nursing model.

Morrison: Well, I'm not really sure that it was or is a nursing model. From the scientific point of view, a model is a theoretical design that's been looked at and studied, and it's written out, and you essentially follow it on a diagram. With the San Francisco model, that didn't happen, because everything just kind of came together. And certainly a lot of the San Francisco model did come from other models that came into play, and I think actually the "nursing model" did as well. Probably the first thing that I related to, because it was kind of at its height at that point, was what was referred to as the model of primary nursing. Primary nursing was something that I had latched onto several years earlier, because it just made so much sense in terms of how you provide quality care to people. In the 1970's, nursing made this great leap. Nursing had always been criticized for not really being a true profession. There has always been a debate about whether or not nurses are professionals. Is nursing a profession, or is it something that's natural? Well, as I see it, it is a profession, and I think it's a wonderful profession that actually encompasses a lot of other things.

Primary nursing was this concept that a registered nurse coordinated the care of a patient or a group of patients and provided all of that care. It makes so much sense because of its simplicity, but at the same time, because of the bureaucracies of health care and everything, it's been one of the most difficult things to ever implement. Certainly, there have been hospitals that have gone to primary care models. And the models where it truly worked were in critical care units, where you would see registered nurses in one-on-one caring for patients. And it works; it's great. You've got accountability; you've got quality of care; you have continuity; you've got all those things that really tend to work.

I had studied the primary nursing model and played with it and had thought about how it could be expanded. I had often said that primary nursing is the only way that nursing is ever going to be considered valid, because our ranks are diluted with paraprofessionals and nonprofessionals. We had pretty much abdicated our responsibilities at the bedside; we were always at the doctor's side or at the nursing station, and the person that was at the beside was at best an LVN [licensed vocational nurse], but usually an orderly or a technician of some sort. So I was very much into primary nursing. That was the core of where I was coming from.

Psychosocial Services

Morrison: The other piece of that, which was not an integral part of nursing, was because of my mental health background and because I had done administration and had a business degree, I was looking at the other things that affected nursing, but particularly the psychosocial. There had never really been an attempt to pull in the psychosocial perspective. Nursing was talking about primary care mcdels and things like that, but we were pulling away from the other professions, because we lost-well, I'm not sure that we ever really truly had an identity. So nursing was struggling with its own identity, and here was this way to do it. But by doing it, we were isolating ourselves.

- Hughes: I see that.
- Morrison: I was certainly aware that I wanted to use primary care. That was the thing that I started saying to everybody right away. Nobody really responded to me. Even Maryanne McGuire thought, [skeptically] Well, yeah, that makes sense. The problem, as always, is that health care is driven by economics. That's what we're seeing today. But it was just as true then, but I think in a different way.

I remember when I started talking to Maryanne McGuire about, "This has to be an all-professional R.N. staff [on 5B]; it has to be an all-R.N. staff," because of all these issues. And she was like, "We can't sell this, because it will cost too much. Sure, we know that primary nursing is the way to go with this, but this is a county hospital. We've got lots of L.V.N.'s. We've got lots of aides and orderlies. We can't promote something in this institution that doesn't include these other people. We'll be crucified for it."

So I began to think about the individual roles, and I said, "Okay, all right, in hiring the staff, let me come up with criteria. We need nurses that have either critical care backgrounds or intense medical nursing backgrounds, preferably people that may have also worked in hospice care, home care. And it would really be nice to have a nice mix of staff that perhaps had mental health backgrounds, because we need to pull all of this in." At that point, I was thinking about my experiences with Shanti, but wasn't thinking of Shanti having a formal role in the hospital, at that time, anyway.

Hughes: Was it because of your experience with Shanti that you realized that the needs of the patients were more extensive than what a hospital could provide?

Morrison: Oh, yes, definitely.

- Hughes: What prompted you to think in terms of community services?
- Morrison: My own experiences. I became the AIDS inpatient coordinator, and everybody, including me, thought, Well, with a handful of

patients, one clinical nurse specialist should be able to handle all of this. And since I had this vast amount of experience in doing all these different things, it made sense. Well, I immediately realized I was in over my head. There was no way one person could do this. I might have the experience; I might be able to coordinate it, but all these different pieces were just too intense. The needs of the patients were too great. You couldn't just come in and say, "All right, I'm going to deal with the physical and the psychosocial issues with this patient," because the physical was a big piece in itself, but the psychosocial was this enormous thing that was all-consuming, and it really took a lot of time and effort. And because I had been doing all this work with Shanti and really believed in what Shanti was doing, I was trying to find a place for it.

We had this designated unit, which was 5B, and we were going to do some modifications on it, add some sinks and stuff. I went ahead and moved my office in there. Well, the rooms were essentially sleeping rooms for the doctors at the time, so sometimes there would be doctors coming and going, and it was right next door to one of the medical intensive care units. But most of the time, I would just be in there working at my little desk, which was a funny-looking little thing; people used to make fun of me. I used this little rickety table.

Patient Input

Morrison: I'd be working on something and I'd think, Oh, I need input from a patient. Since I knew all of the patients in the hospital who had a diagnosis of AIDS, and saw them all as often as possible, I'd go get one of them. People weren't relating to them anyway, because they were still pretty much ostracized, and there was still all this fear and stuff.

> On the one hand, we were doing this planning, but on the other side was this other big crisis in the institution, with the staff going crazy because of media attention about, "Is AIDS going to kill everybody?" Talk about a mess at that point. I was fortunate in that nobody paid that much attention to me, so I could go about doing what I needed to do without anybody interfering with it too much.

Hughes: Is this early 1983?

Morrison: Yes, early '83; by the time I was at that point of doing this planning. I'd go talk to patients and I'd say, "We want to set this unit up right. What's your idea about this particular point?"

So I remember one day there were five or six patients that were ambulatory, and I just went and got them all and put them in wheelchairs and brought them over to 5B and put them in a circle. We sat there, and I was like, "I'm stumped. What can we do to meet your needs in this setting?"

And that was the smartest thing I ever did, because it became really clear to me at that point that very little of it from the nursing perspective had anything to do with medical care. It was all psychosocial; it was all control issues; it was all education; it was all about inclusion; patients having a role in making decisions; patients being amply informed; patients' rights. One of the first things a patient said to me was, "I want to be able to control whom I see and when I want to see them. I don't want the institution dictating that to me. I don't want the institution to define my family; I'll tell you who my family is."

Visiting Rules

- Morrison: I'm not sure that it's clearly documented, because it gets edited out of a lot of stuff that I've written, but I've certainly said it to enough people: I really and truly think that one of the biggest contributions I made was the policy at San Francisco General regarding visiting hours and families. I wrote that policy myself. Actually, I had come up with it before, during the planning of the unit, but after the unitopened, I had had some experience in writing policies. Well, I don't know how much you know about the archaic bureaucracies of hospitals, but great importance is placed on, "This is the hospital policy," which nobody uses until they have to justify a situation or a particular stand.
- Hughes: Back it up.
- Morrison: Until they have to back it up, exactly. Or it's an excuse: "You can't do this because it's hospital policy." Well, why? It's ridiculous. "Because it's the policy. It's the rule. That's the way it's supposed to be." So I certainly knew how to write them, and I also knew that they had to go through all these committees before being accepted.

The SFGH Infection Control Committee

Establishing AIDS Infection Control

- Morrison: The greatest ally for me at that point was the infection control committee. I became a member of the infection control committee, and I would go to them with policy issues, patient care issues, and bounce things off them. Grace Lusby was our infection control coordinator, and she was a wonderful resource for me.¹ We were together through all of that. We went through it; we suffered together. We closely identified a lot.
- Hughes: Well, I'd like to show you a document.² [tape interruption] I was amazed to find what a central role the infection control committee had in formulating 5B.
- Morrison: Yes. I remember working on this. And from this came one of the first articles, and it got published, and my name got left off of it. It became a real big issue, because Merle felt bad about it and oftentimes would say, "Well, Cliff, you signed off on all this," and I used to say, "But when it was printed, my name wasn't on it."

Hughes: Now, this is the <u>New England Journal of Medicine</u> article?³

Morrison: Yes.

- Hughes: Well, Grace made quite a point in her oral history that most of those policies had been pre-established by the infection control committee, as opposed to Sande's AIDS task force.
- Morrison: Yes. She's right. He would argue that, for a number of reasons.

Hughes: What were Sande's arguments?

¹ See Lusby's oral history in this series.

² Inpatient isolation procedures for patients with Kaposi's sarcoma and other acquired immunodeficieny syndromes. [February 1, 1983] AIDS Resources Center Archives, Ward 5A, San Francisco General Hospital, unlabeled off-white file box.

³ J. E. Conte and members of the AIDS task force. Infectioncontrol guidelines for patients with the acquired immunodeficiency syndrome (AIDS). <u>New England Journal of Medicine</u> 1983, 309, 12: 740-744.

- Morrison: I would have to research a lot of old material to find it, but it was particular infection control issues, use of masks, visitors, etc.
- Hughes: Can you recreate the tenor of discussions of the infection control committee?
- Morrison: They generally came about because of a crisis. This document was a direct result of the lack of quality of care of patients with an AIDS diagnosis at San Francisco General. If they weren't in the critical care units, then they were stuck in rooms at the end of the hall that nobody ever went in, the rooms were never, or rarely, cleaned, their beds were never changed, their food was always sitting outside the door, that sort of thing.
- Hughes: What units had AIDS patients in those early days?
- Morrison: Well, you see, San Francisco General is much smaller now and much more condensed. Some of those units are no longer there. 4C was family practice. It had a large number of AIDS patients. 5C was the major medical unit; it had a significant number. 5D was medical step-down unit, and it had patients. And then of course, all the critical care units. That's where most of the patients were.
- Hughes: Was there segregation according to symptomology? Would PCP patients tend to be in one unit as opposed to another?
- Morrison: Not necessarily. AIDS is pretty much a medical illness. There's not a lot of surgery usually applied to it, so the patients were in the medical division. And they just pretty much went where there were beds available.

Now, what we identified very early on, 5C wound up getting most of these patients. 5C is still the major medical unit at San Francisco General. I identified, and so did Grace Lusby and a number of other people right away, that 5C was doing the best job. By and large, most of the nurses seemed to have a little bit more compassion. They weren't as upset by it. They'd already seen enough AIDS patients, and all of us had spent a lot of time working with them, so the patients got better care on 5C. I was often able to say that a good chunk of the nursing staff that became the original core staff of the AIDS unit came from 5C. I used 5C for orientation of new staff as they came in before we even opened the unit, because I set up all this fairly formal educational process of training programs for nurses before we even got to opening the unit.

Hughes: And those training programs occurred in 5C?

Morrison: Yes, 5C and 5D.

- Hughes: So a nurse that eventually was going to be on what became 5B would have had to spend time in one of those other units?
- Morrison: Exactly. They all came through, and before 5B opened, yes, they worked on 5C and 5D. The head nurses in those areas worked closely with me, and I developed individual educational programs for the nurses: "This is what I want them to focus on; this is what I want them to do."

Comparison with Sande's UCSF AIDS Task Force

- Hughes: I want to hear a lot about 5B, but let's first continue with the infection control committee. Tell me if you can what indeed was the difference between the infection control committee and Merle Sande's committee.
- Morrison: Yes. The infection control committee is a standing committee in the hospital [SFGH]. It was there. By virtue of the fact that this was an infectious disease, it was within their domain. Dr. Sande being the chief of medicine realized early on that there was going to always be controversy associated with this disease. A lot of people would speculate as to exactly what his motives were, but I like to think that they were for the right reasons. He knew that any decisions that were made were going to be controversial, and he felt that he needed to have as much input and support from other people as possible, so that when it does hit the fan around here, that I can say, "Hey, I didn't make this decision in isolation. I had all these other people. Here was Cliff, here was Grace, here was Dr. Abrams, Dr. Volberding, all the docs from UC were involved." So that was the difference between the committees.

Sande's group [UCSF AIDS Task Force] was more of a brainstorming group--brainstorming really is not the term. Almost all of this stuff at that point was crisis-driven. It was crisis management at its ultimate.

Hughes: Were they tense meetings?

Morrison: Oh, yes, they were tense. We were always trying to catch up. It first happened in these meetings, like the first thing we'd start off with was dealing with a current crisis. What kind of isolation? This was the first issue that we started fighting with. Staff and physicians and everybody else was saying, "This patient has got to be totally isolated. We don't know what we're dealing with here; we don't want to touch them," this sort of thing.

And then the voice of reason was the infection control committee, by and large. Most of the people on it were fairly rational. Not everybody, by the way.

Hughes: Because they went back to their infection control training?

Morrison: Exactly. Now, I would say the two people that really played major roles here were Grace Lusby and Connie Wofsy. Connie was the physician that was the voice of reason on the infection control committee and didn't get into the screaming and the yelling and all the other stuff. She would just say, "I'm sorry, folks, this is the way it is. This is basic infection control; this is what we're dealing with here."

> But the infection control committee immediately became a major power broker in this, and then these other committees sprang up--maybe not consciously--to usurp some of that power and authority. But certainly the infection control committee was the central thing. Everything that I was doing, I ran through the infection control committee first.

Hughes: Even after Dr. Sande's committee was up and running?

Morrison: Oh, yes. Because it was the infection control committee for my institution [SFGH]. Dr. Sande's committee was UC, and certainly played a major role, because that's where we respond to the crises. "What are we doing with this? Because the media is screaming about this." Or, "What are we going to do with this, because we've got this patient, we've never seen this kind of a symptom before." Whereas in the infection control committee, we were dealing with the nuts and bolts issues: "Do we wear masks or don't we? Do these patients have to be in isolated rooms? Can two patients be in the same room together?" Those were the kinds of things that we were dealing with in the infection control committee.

The CDC's Role

Hughes: Cliff, what was the input, if any, from the CDC?

Morrison: CDC, I think, had input. There were [CDC] representatives coming in and out all the time. Dr. Curran came out often. I don't remember him coming to an infection control meeting maybe but once or twice, but he went to Dr. Sande's meetings a lot. And he was always a voice of reason. I liked him a lot. I thought, "Well, here's somebody from the political establishment who doesn't really seem to have an axe to grind and is able to look at it objectively."

- Hughes: Was the CDC any help in formulating the policy for AIDS infection control?
- Morrison: I'm not sure CDC itself was. I think Grace was talking to people at CDC. I know Connie definitely was, also Paul and Merle. Dr. Curran himself probably influenced it more personally than CDC itself did. Because CDC is a big bureaucracy, so if anything goes to CDC, it's got to go through all this bureaucracy. Whereas Curran was able to say, "Well, based on my experience and my position here, I would suggest, or I would recommend, or this is my feeling about it. Yes, what you're doing is a little controversial, but there's no reason why you shouldn't do it."
- Hughes: Was he basing his opinions on his general knowledge of epidemiology, or was he basing it specifically on the epidemiology of AIDS, which of course, CDC was the primary proponent?
- Morrison: Both, I think. See, that's where I think the infection control committee came in. The infection control committee did a very good job of sticking to, "Okay, let's forget AIDS. Let's don't even talk about AIDS. Let's talk about basic infection control." And that's where I heard Curran and people like him coming from as well. They tried to go back to that, "Let's don't make this thing bigger than it is. What it is we're doing, let's back it up with science. Let's don't create something new. Let's just back it up with what's already there."

The Hepatitis B Model

Hughes: And that was the hepatitis B model of infection control?

Morrison: Yes. Grace would know the history of how all of that came about. The director of infection control and epidemiology at UC San Diego developed that whole HIV/AIDS model for body/substance precautions. Her name is Marguerite Jackson; she's a nurse. She's still there. She's a wonderful person. Believe it or not, she and I are from the same area as well. [laughter] Her accent is so deep, it's unbelievable. People are like, "The two of you came from almost the same little town? Her accent is so much deeper than yours."

But yes, we tried to back all this up with science. The difference was, the infection control committee pretty much based its decisions on science and the principles of infection control, and its meetings were closed. It was a working committee, dealing with all the other infection control issues in the hospital, but certainly AIDS all of a sudden became the major focus.

Rejuvenation of Infection Control

Morrison: Now, the other thing that Grace might have alluded to, or other people, is that AIDS basically reinvented and reestablished infection control. Infection control committees really had very little clout. Nobody paid much attention to them. And the general feeling was that we had pretty much conquered everything. What do you need an infection control committee for? It was just one of your standing committees.

> AIDS refocused everybody on basic infection control and made us go back to basic science. People ask, "What was the first thing you did?" "We told people to wash their hands." [laughter] And you know? Media people didn't want to hear that at all.

Hughes: That's not technologically innovative.

Morrison: Exactly. What's the big deal here? The world's not supposed to know that nurses and doctors don't wash their hands enough. Well, we still don't. That's part of the problem. But it [AIDS] basically reestablished and reaffirmed infection control and put it back on the map. This committee certainly was not in the spotlight, and all of a sudden it was in the spotlight. So all of a sudden, it became <u>the</u> important committee in the hospital.

Debate over Resuscitation

UCSF AIDS Task Force

- Morrison: Now, Dr. Sande's group was more of a consensus group. It was where things got batted around--ideas, philosophies, specific issues related to care, policy issues, the global thing. The infection control committee dealt specifically with the basics of infection control and epidemiology. Dr. Sande's committee tried to handle everything, and it was a brainstorming group and pretty much operated by consensus.
- Hughes: Did it tend to get more media attention?
- Morrison: Yes. The media hardly ever heard anything about the infection control committee. First of all, the term is a real turn-off to them.

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- Hughes: Apparently there was a fiery debate about the right to resuscitation.
- Morrison: Oh, it sure was.
- Hughes: And it caused tension in the outside community as well.¹
- Morrison: It did.
- Hughes: Was that issue debated in both committees?
- Morrison: It was debated in both. Not as much in infection control. In the infection control committee, the procedures for resuscitation were debated: how to do it and do it safely. Whereas in Dr. Sande's committee, it was whether or not to do it at all.
- Hughes: Right, and that's what caused the tension.

Morrison: Yes.

Hughes: Sande's committee decided that resuscitation did not have to take place if there weren't proper means available to prevent

¹ Bobbi Campbell. U.C.'s brand new let 'em die guidelines for AIDS patients. <u>The Sentinel</u>, September 9, 1983.

mouth-to-mouth contact.¹ Can you recreate some of the discussion?

Morrison: I can, because this is one of the things that grew out of the nursing involvement. It was nurses that first started identifying this and made it a real issue. It was an issue, but nobody was dealing with it.

Patients' Opinions

Morrison: Patients that were saying to me and to other nurses, "I don't want to be resuscitated," and we were resuscitating them anyway. We were bringing them back to life for nothing but to suffer more, particularly at that point. It took us back to this basic premise that I'd been preaching from day one about patients need to be part of this partnership decision-making. I used to say over and over, "Patients need to be educated; patients need to be informed; they need to be part of the decision-making. We're doing all this stuff to patients, and they don't even know what in the hell is going on, and then when they find out about it, they don't want it. But we do it anyway because we think we know best what to do for them." That's where it came from.

> DNR, Do Not Resuscitate, has always been controversial. It's always been something that nobody wanted to deal with. AIDS probably more than anything else pushed all of these issues--everything that we had never dealt with in health care. All the ethical issues were thrown on us all at once. And it was mind-boggling. It was scary, and it was a real exercise to go through some of that stuff.

There were times I'd walk out of those meetings, and I'd be reeling. My head would be hurting. I would come home sometimes at night and I'd be like, "God, there's so many issues going on. I can't ferret them all out." I could go into work one morning thinking that I'm going to deal with this issue today; and by the end of the day, there would be a dozen more.

Hughes: And no time to really deal with any one of them?

¹ David Perlman. New safeguards urged in AIDS emergencies. <u>San</u> <u>Francisco Chronicle</u>, September 22, 1983, p. 8.

Morrison: No time to process them, no time to really come to any sort of logical closure with any issue before you moved on to something else. And none of the issues were in isolation--good choice of words. [laughs] I mean, every issue was dependent on another issue, so it all just compounded and kept getting bigger and bigger. It was such a mess.

> Dr. Sande, who conducted these meetings, really was very good at being able to articulate it, and you could see it in his face, "This thing is just so huge. Nobody really realizes what we're dealing with here, and we've got to get control of it."

That's why I've always said that the issues of this epidemic were control, at every single level, whether it was the patient, whether it was us, whether it was the systems, the bureaucracies, or whatever. Everybody was trying to maintain control, and maintain control the old-fashioned way, the way that we'd always done it, within their disciplines and within the hierarchies. And I think what happened for a number of us was that the underlying rules were changing so quickly that a lot of us couldn't keep up with it, and it was very threatening to a lot of people.

Nursing's Role

- Morrison: I think particularly that the role of nursing changed a lot during that period, in that for the first time we were at the table. We were major contributors to policies, to the decision-making process.
- Hughes: Were you an invited member of Sande's committee?
- Morrison: Yes.
- Hughes: Grace said that she and some other infection control people just appeared at Sande's meetings; they weren't formal members of the committee.¹

Morrison: They weren't invited.

Hughes: Yes. But they felt this was their area of expertise, and they should be there.

¹ See Lusby's oral history in this series.

- Morrison: She's right. I'm not sure Grace was invited; I'm not sure that several other people were invited. I was. It was interesting that Dr. Sande said, "I want you to come." Maybe the first couple of meetings, it was obvious that there were some people who should be there that weren't. I'm not criticizing him, because there were meetings going on all over the place at every level. When other people appeared at the meeting and said, "I have something to say here," he was open to hearing it. And that's how the group grew.
- Hughes: But is it not true that initially his committee was a physician-dominated committee?
- Morrison: Oh, yes. In fact, it always was.
- Hughes: It remained so. And the others only came in either as an afterthought or because they themselves said, "I need to be here."
- Morrison: As an afterthought, and I think also because Dr. Sande realized that all of this was so controversial, and that when it did hit the fan, that he needed to be able to say, "Look at all these people that supported it. There were social workers here, there were psychologists, there were nurses, there were..."
- Hughes: Well, you gave me a different slant on resuscitation, that indeed no resuscitation was often exactly what the patients wished. But aren't I right that the media twisted it the other way? That the hospital was letting patients die.
- Morrison: Yes, was letting patients die. Or the media would go to the other extreme: it was against patients' wishes, intubating them and keeping them alive. So it was one or the other. The media was always extreme with it.

And where nursing was coming from was, DNR, Do Not Resuscitate, was okay. But in order for it to happen, you had to inform and educate your patients. I used to say, and I said in all those meetings at that time, "Let's don't find ourselves in the situation where a patient is coding," meaning that we're doing this resuscitation, "and we're standing there deciding, Well, should this be done or shouldn't it? From the time patients come into the system, let's include them, start educating them, letting them know what their options are along the way, and let the patient either make the decision or contribute to the decision." Some patients are very good at it; others don't want that kind of participation, but most of them did. I found out very quickly that patients oftentimes were much more educated than us and were responsible for bringing us a lot of new information. In regard to resuscitation, the majority of them would say, "Okay, I want to put parameters on this. I want you to do everything you can for me until this point. If I reach this point," whatever that point would be, and it was usually, "I'm intubated; there's not anything that's going to help; the quality of my life has diminished to such a point that I'm never going to be able to have any real quality of life again, then I want it ceased. I don't want to go any further with this." So these policies grew up out of that premise.

Collision of Nursing and Medial Premises

- Hughes: That defies a medical model, which is, you do everything you can to preserve a person's life.
- Morrison: Yes. And there were arguments about that.
- Hughes: Is preserving life at all cost less predominant in nursing than in medicine?
- Morrison: Yes, because caring for people encompasses quality of life issues.
- Hughes: How much had your training been oriented towards preserving life?
- Morrison: The difference is--and this is the fundamental difference between nurses and doctors, and it really got played out in both of these committees--medicine focuses on curing and keeping people alive. For a doctor, the worst thing in the world that can happen is for a patient to die. The patient has failed them, or they have failed. And we inadvertently give that message to patients, that the worst thing in the world that can happen is that you die.

That's not nursing's premise at all. Ours is caring. We're patient advocates. Our whole focus is on taking care of people, ensuring quality of life, advocating for them, educating them, preventing illness--that's nursing. So yes, there is a fundamental difference. When you put it in this context [AIDS], all of a sudden there was a collision. The interesting thing is that in this collision, it was probably one of the first times that, quote, "medicine" began to listen to where nursing was coming from. And then we got support from social work and from psychiatry, where all these psychosocial issues came into play. I think it was very threatening and overwhelming to a lot of physicians at that point.

Hughes: So nursing was educating not only patients but also physicians.

- Morrison: We were.
- Hughes: For one of the first times in history?
- Morrison: Well, I think nurses have always been educating physicians. I don't mean to say that we taught them everything they know. But you go to any teaching hospital, and you will see that nurses are teaching physicians, informally.
- Hughes: And physicians will sometimes admit that.
- Morrison: Yes. I've certainly learned a lot from physicians, that's for sure. But I think that it works both ways. But oftentimes, because of the way the educational system is set up, nurses are in a position to teach doctors a lot of different things. Dr. Silverman and I used to joke a lot that I taught him what nursing is about. Because he had worked so much with nurses, he really began to look at it differently. He'd be one of the first to tell you now that medicine oftentimes acted in a vacuum, and didn't consider other points of view.

The Hospice Model

Morrison: But certainly, I think that there were precedents for it. We'd already seen it in oncology, particularly in hospice. I pulled in hospice as part of this other San Francisco model. Nursing and some of the other disciplines were promoting hospice, but hospice really had not taken off in this country in 1982-'83. It was there, but we rarely talked about it. Nobody wanted to use it.

Hughes: Had you had any direct experience with hospice?

Morrison: Yes, I had. And it had been very positive. I had already read all of Dr. [Elisabeth] Kübler-Ross's books and was very fascinated with them, and began to think, Hey, this is an area that I want to focus on. So I was aware of those issues, but certainly they all came into play at one time.

Still More on Ward 5B

Money Matters

- Hughes: Let's go back, because I have some more questions about actually setting up 5B. One is, was the funding coming exclusively from the city's budget surplus?
- Morrison: For the inpatient unit certainly. Yes, it was from city government, through the mayor, through the Department of Public Health, through Dr. Silverman, filtered through the hospital.

Hughes: So money, in essence, wasn't much of a problem?

Morrison: Well, looking back on it, certainly not to the point that it is today. People were always saying, "Well, we don't have unlimited funds here, and this is going to cost money." But because of the crisis of the moment, and the fact that there was the surplus, a lot of things happened that certainly, if it happened today, just wouldn't have flown.

> The other thing was that, even with the budget surplus, a lot of what we did didn't cost. For the first time, we introduced volunteerism and had large numbers of volunteers working at every level. That was threatening, because San Francisco is a highly unionized town, and there was some concern, Hey, we're bringing in all these volunteers, and they're doing things that paid union members do, or should be doing. So there were questions about all of that. We saw that, Hey, there's a lot of manpower here. And that's part of the cost.

We still don't have a handle on the cost of care for people with AIDS. We throw figures out all the time, but nobody really knows what the real figure is, because so much of it has never been costed out, and the volunteer piece is part of it. But even within the hospital setting, we don't have a good grip on it.

Hughes: Yet, isn't it true that one of the motors of the San Francisco model was the economic--

- Morrison: The cost-effectiveness.
- Hughes: Yes, you can reduce hospital time if patients can turn to community support organizations.
- Morrison: Well, we talked about cost-effectiveness a lot. But again, I think it was nursing that said, "Yes, cost-effective, but quality is the important issue here, quality of care, quality of life. The bottom line is not economics here; it's quality of life."

Staffing the Unit

- Hughes: You mentioned staffing the unit, and the training that went on in 5C. Would you talk about what you were looking for when you interviewed? And I understand you interviewed a lot of people, which was a surprise, right?
- Morrison: Yes. I was able to sell the primary nursing model for the inpatient unit, not by saying that it was a primary nursing model, but by saying, "Well, because of all the issues associated with this [AIDS], we're going to have to have registered nurses caring for these patients, because we're not going to be able to get anybody else." And I remember it got discussed some at Dr. Sande's meetings. They said, "Well, gee, the only people who are going to work in it are gay male nurses. Do we have enough? Will we have people that want to do it?"

Well, I remember I said at that point, "You're not going to have a staff of gay male nurses," because at that point, it wasn't gay male nurses that were stepping forward. Yes, there were one or two, but by and large, the gay male nurses were kind of like, "Oh, my god, what is this!? I don't want to be associated with this."

Hughes: Because it was too personally threatening?

Morrison: It was too personal, yes. And the first people that really came to my aid as nurses were straight female nurses and lesbians. I will always be indebted to the women in this community who did that.

Hughes: Why those groups particularly?

It's complex, and a lot of people have asked me that. I think Morrison: a lot of it has to do with why people are nurses in the first place, whether they're male or female. Straight women by and large don't find the issues of sexuality as threatening as straight men do. Again, this is Cliff Morrison speaking. I think that women just tend to be more sensitive to the issues, aren't as threatened by them, and in some respects have a very healthy curiosity about it. Grace was one of those people. Grace was fascinated by it. I used to have to say, "Grace, get a grip!" [laughter] Grace was one of these people that was just totally enthralled with all of the sexual behaviors. But she wasn't the only one, so I don't want to criticize Grace. She wasn't offended by any of it. She wanted to know more and more and more, and that was pretty much, I think, where a lot of the women were coming from.

> Lesbian nurses had a totally different approach to it. Diane Jones was certainly one of the first ones, and one of those people that I will always hold in high esteem and will love forever. She can do no wrong in my eyes. They knew that they weren't at risk, even at that point, but they saw it as a bigger issue. One of the things that I think the public really wasn't aware of is that there was, particularly in this community, not a lot of cooperation, not a lot of good feeling between lesbians and gay men, because we were all competing for the same little piece of pie.

> And then all the other issues came into it, too, and of course, the stereotypes: if you're gay, whether or not you're male or female, it means that you hate the opposite sex. Well, that's not the case. It has very little to do with it. In fact, in many respects, it might be just the opposite. I'm sure that one of the reasons why I love nursing so much is because I <u>much</u> prefer to work with women than men. I relate to them much better; I relate to their sensitivity, to the fact that I can talk to them about different things. There's another side of that, too, where sometimes I'm like, god, why am I working with all these women? [laughter] So my own internalized sexism comes out, internalized homophobia. So we learned a lot about ourselves.

> I remember Diane and others saying, "Hey, this goes beyond being lesbian or gay male. This is an issue for us as a community. We have to be united on this. I have an obligation to step forward and do what I can for my gay brothers." I remember her saying that, and I think that said it all. So they were wonderful.

One of the first gay male nurses was Steve Keith. I think he's still there part-time. And Bill Nelson. Bill Nelson works for the state now. I have a photograph of the original nursing staff.

Burnout

- Morrison: Diane and I might be the ones that have come out the best, and maybe Alison [Moed] too, in terms of reaching middle age and still having our health and some sanity. Many of the others paid for it in other ways. Kathy Juristo, who was the oldest nurse, died of cancer a few years ago. Bill Nelson, who was the first nurse to come on, and he was only a year older than me, I believe, has had a heart and lung transplant. Everybody has just had horrendous medical problems and things in their lives.
- Hughes: Do you see the medical problems relating to their work on 5B?
- Morrison: Not 5B; I think the issues related to the epidemic and the intensity of what we were in, and some of it contributed to lifestyle too. Let's face it: if any of us didn't have a drinking problem when we started, we certainly picked it up later on, believe me. Whether it be smoking cigarettes or drinking alcohol or whatever, we all found whatever crutches we could to get through it.

Staffing (Continued)

- Hughes: I see. Well, continue with what you were looking for in a job applicant.
- Morrison: The ads that went out were pretty blunt: "Seeking nurses to work with patients with AIDS. Preferably critical care experience, hospice experience, mental health background," that sort of thing.
- Hughes: But no explicit issues about sexual preference?
- Morrison: No. Once they came in for the interviews, yes. Everybody made an assumption that the staff would be all gay, whether it was male or female. I remember even Dr. Sande saying, "Oh, well, if you do get staff, it's going to be a gay staff. Who else is

going to want to take care of these patients?" That wasn't what happened.

Hughes: You didn't think sexual preference was important?

- Morrison: No. I never did, and made it clear from the beginning that I didn't think so. One of the first nurses was Alison Moed. Alison was a straight woman who was a nurse on 5C. I met Alison because I went over to see the AIDS patients, and she and I bonded almost immediately. I remember she said, "I want to work on this unit. Let me know." Of the original twelve nurses--and I'm not counting myself in that, because I was thirteen--six were gay and six were straight. So it evened out. Now, it is true that all of the males were gay, but the women weren't.
- Hughes: Was there ever any feeling that, "Because I am gay, I have a greater understanding of these patients and their needs and therefore can take better care of them than you, a heterosexual?"
- Morrison: That's been an argument all along. I think people wanted that to be the case, and I think there were even nurses in the original group that felt strongly about that. I didn't realize until maybe even a couple of years later that there was some feeling among some of the gay staff that I went about it all wrong. Not all the staff agreed with me. Maryanne McGuire let me do this [establishing criteria and selecting staff] myself, and she looked at them as I would present them to her, and she was like, "Are you sure these are the people you want?" I'm like, "Yeah."

Maryanne said, "You've got nothing in here but rabblerousers, troublemakers. These people are going to make your life miserable," not to mention hers. And she's like, [doubtfully] "I don't know. I trust you, but I hope you know what you're doing." I said I did; I didn't. [laughter] I hope that at some point in my life I will have feelings like I had then. I've heard a number of people who were in that position, when we were all coming together, that have said, "I have never since felt anything as intensely and so strongly about what was right, and what was the thing to do."

I resisted all of this emphasis on "gay." I downplayed the fact that I was gay. Everybody knew it, but I tried not to mention it too much. I didn't want to make that the focus, because the media and everybody else wanted to do that too. Some of the first interviews with the media were, "Well, I'm assuming all your nurses are gay." "No, they're not. And please don't make that assumption. That's very unfair to a lot of people."

The straight nurses that worked on the unit often found it amusing. In fact, one's still there, works part-time, Ann Steinlauf. A fascinating woman; I just love Ann to death. Very fascinating, complex woman, very quiet. Nobody ever really knew Ann that well. People questioned me, "Why did you hire her?" She was <u>strong</u>. I liked it. [laughs] She was just out of nursing school.

- Hughes: You mean psychologically?
- Morrison: Oh, yes. This was a woman who had had personal suffering in her own life. She'd had a difficult life, but she was a balanced person, a compassionate person.
- Hughes: You were specifically looking for those characteristics?
- Morrison: Yes. Those were the things I was looking for. People made an assumption, probably with Ann more than a lot of the other women--again, stereotypes--that she was gay, and she wasn't. She thought it was funny. She never took it personally. She was like, "Eh, I don't care." This was a woman who had a boyfriend--I think they're still together fourteen years later --I mean, he's gorgeous. [laughter] We all wanted him! And still do. But yes, she was great about it, as I think most of the others were too.

I wanted, first of all, people who had good, basic nursing experience. Maryanne McGuire and I talked a lot about what it was that we were looking for. I said, "We need nurses who have got good clinical backgrounds, so it would be important to have a couple of people who had been in nursing for a long time, who are your staunch med-surg nurses, because that's so important; we need that.

"At the same time, it's probably okay to have a mix here. We can bring in a couple of new graduates who have never worked in nursing before, because we'll have a balance here." A lot of compromises were made, because we weren't going to hire the nonprofessional-paraprofessional staff. There were two people, George Jalbert and Bob Adrian, that applied who were both in nursing school. They were males, and they were working at San Francisco General as orderlies, but they were called orderly trainees. Maryanne McGuire had set up this wonderful program to encourage staff to go back to school. Nursing has always been good about nurturing people to go back to school. Both of these were gay men, and both were in their last year of nursing school--

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Morrison: --and they really wanted to do this. So we knew that we needed to have different mixes of experience, so we brought them on. They were the only non-nurses, and both of them finished nursing school within a short period of time and then passed state boards. But yes, we were looking for this mix of experiences and background.

> More importantly, the personal stuff. The first thing I would ask applicants was, "What's your feeling about working with people with AIDS?" That was, to me, the most important thing. Later on, I would say, "How about issues of sexuality? How uncomfortable are you with that?" A number of people said, "I don't know. It's never been an issue before."

> I had a series of open-ended questions, and that's the nature of them: "How do you feel about death and dying? How do you feel about issues of sexuality? How do you feel about caring for young people that are dying? How do you feel about the role of family? Do you think there's a role for significant others or partners in all of this?" I was trying to find out where people were coming from.

> I took notes, so that it could be as fair as possible, and came up with this real diverse mix of people. I wanted a mix of gay and non-gay, but I also wanted a little bit more cultural diversity, which I didn't get at that point.

- Hughes: It was pretty Caucasian?
- Morrison: Yes. Our unit secretary was African American, but all the rest of us were Caucasian.
- Hughes: And that was because of your applicant pool?
- Morrison: That was the applicant pool, yes. Now, later on, we did get that, and I think now it's a pretty good ethnic mix on the unit.

The Clinical Nurse Specialist

Role

- Hughes: Well, in several of your articles, you've spoken of the need for an institution to appoint an individual to be coordinator of AIDS activities, and have suggested that a clinical nurse specialist is the best person to have in that position.¹ Would you like to expand?
- Morrison: Yes. Well, because the clinical nurse specialist was a new role, and that's how I was educated. I was a clinical nurse specialist. These are graduate-prepared nurses, and clinical nurse specialists can be in any of the specialty areas.

The role is much more dynamic. Clinical nurse specialists are people who have excelled in their clinical area of expertise, but also like to teach, also are interested in expanding their role and being involved in policy-making and education, and just taking it a whole step further. It was the first time in nursing that we had a role that in any way could be compared to what physicians did. See, nursing still is traditional in that if you're a clinical nurse, you don't do academia. If you do academia, you don't do clinical. And the same with research: if you do research, you don't do clinical. Whereas medicine has always been up on us in that area, because almost all of your physicians in academia, they may be doing research, they may be teaching, but they also have a patient load.

Clinical nurse specialist kind of emulated that, but in a different way. Most of us also had faculty appointments, and our primary responsibility was to be role models for nurses. We were to identify clinical issues on the unit. The first thing that clinical nurse specialists do is establish a relationship with every individual staff person on a unit, and let them know, "Whenever you come upon a problem, when you identify an issue, come to us and we'll problem-solve it with you; we'll work it through. If we need to develop classes for people around this, then we'll do it." It was a role that grew

¹ See, for example: Cliff Morrison. Nursing perspectives in the care of patients with AIDS: Experience from the AIDS unit of the San Francisco General Hospital. In: <u>AIDS, Acquired Immune Deficiency Syndrome,</u> <u>and Other Manifestations of HIV Infection</u>. Gary P. Wormser, ed. Park Ridge, NJ: Noyes Publications, 1987, pp. 1082-1095.

specifically out of the need to look at the quality of care that was being given to patients. Well, I took to the role like a duck to water. It was <u>exactly</u> what I wanted, and I loved it. I loved the role of clinical nurse specialist.

Hughes: Why did you feel that the clinical nurse specialist was the best person to be AIDS coordinator?

Morrison: Probably some of it was selfish. [laughter] A lot of it was.

Hughes: "I'm one, so that's how it should be."

Well, yes, because it was obvious to me that, for the first Morrison: time, here was a clear role for the profession of nursing. Who better within nursing to do this than the clinical nurse specialist? We had these broad roles, because of our clinical and educational preparation. We all had to have graduate degrees. In order to become a clinical nurse specialist, you have quite a bit of experience in nursing, so you're used to working. Also, the focus of clinical nurse specialist is to incorporate the psychosocial, to work with the other disciplines. So we had a whole leg up, so to speak, on experience in working with other groups and with reaching out, pulling people in, and looking at the big picture. Whereas everybody else in nursing was more focused on their narrow roles, including nurse practitioners. And when I say "narrow," I don't mean that in a negative context.

> It was important to have those skills, and to have a nurse in that role, because a nurse with the proper background, credentials, and experience could bring all of that into play, and could basically identify who needed to be pulled in, when and where and what.

> My ideal of that would be that you would have an unselfish person in that role, who was focusing on quality of care issues and on doing the right thing, more than building their own careers. It was a very fulfilling role.

Hughes: Yes, I can see that. Did other institutions pick up on your suggestion?

Morrison: Oh, yes. Clinical nurse specialists were getting more and more recognized at that time, and I think that we certainly made a big contribution: "Ah, this is clear; this [AIDS coordination and education] really is a role for clinical nurse specialists." It was almost tailor-made.

Contrasted with the Nurse Practitioner

- Morrison: Clinical nurse specialists and nurse practitioners came up around the same time. Nurse practitioner is a direct role counterpart of physician's assistant. That was nursing's response to P.A.'s. Clinical nurse specialist was an internal response in nursing; nurses themselves wanted to do something different with their roles.
- Hughes: How do those two roles differ?
- Morrison: Oh, they differ vastly. Back in those early years, it looked as if the clinical nurse specialist was going to be the important focus in clinical nursing. And now it's reversed: it's nurse practitioners, because of what's happening in health care.

But the roles are different because nurse practitioners function more like physician's assistants, but with the nursing component as part of it. If you go to Ward 96 [the outpatient clinic at SFGH], you'll see nurse practitioners. They have their own patient loads; they see patients just like the physicians and physician's assistants do; they practice primary care. If they identify something that they can't deal with, then they call in the physician, or will refer the patient to somebody who can deal specifically with that issue. It's a much more narrowly defined role, much more parallel to medicine, and nurse practitioners tend to identify more with physicians.

- Hughes: Than with nurses, you mean?
- Morrison: Oftentimes, I think that is the case. J. B. Molaghan is a good example. I like J. B. a lot. [interruption] I think he certainly has a much better understanding of the role differences, what it is exactly that makes nurse practitioners unique.

Nurse practitioners, because of their role and where they come from in nursing, oftentimes will identify more with physicians than with nurses, because they kind of operate outside of what the rest of us are doing. You don't see nurse practitioners as much in the inpatient area. You see them in outpatient, in community settings. Whereas you see clinical nurse specialists more in the inpatient units.

You can't really define the role of the clinical nurse specialist that clearly, can you? There are so many things that we can do, or our roles are flexible. We fill in the gaps. Whereas nurse practitioners, the role is more clearly defined, and the need is clearly defined, so that's where the difference is.

I think there's a place for both. I don't see that it has to be one or the other, and I don't think one is necessarily better than the other. I think they can complement each other and the other health care disciplines.

Medical Direction of 5B

Initial Lack of a Medical Director

- Hughes: Carol Pogash noted that there was not a medical director of 5B for the first few years.¹
- Morrison: Actually, the whole time I was there [1983-1986], there wasn't.
- Hughes: Why was that?
- Morrison: A lot of people have asked that, and I think everybody disagrees on the answer. Because I was the clinical coordinator, I made it very clear, and so did Maryanne McGuire, because nobody else really wanted to deal with this, that this ward was a nursing model, and you don't have a physician in charge of a nursing model. You wouldn't have a nurse in charge of a medical model.

And they were, "Okay, all right, we don't want it anyway." Paul was director of the AIDS Clinic, so he was satisfied with the arrangement. Nobody really knew what was going to happen with 5B anyway, so nobody cared. It wasn't a turf issue at that point. It became one later. So that once the unit was established, because it was a nursing model, I pretty much coordinated it and worked with everybody that I felt was needed.

Now, certainly, all the medical teams came through, and we had all the doctors and everything. Dr. Sande was the chief of medicine, so by default, he was the medical director of the

¹ Carol Pogash. <u>As Real as It Gets: The Life of a Hospital at the</u> <u>Center of the AIDS Epidemic</u>. New York: Birch Lane Press, 1992, p. 106.

medicine, so by default, he was the medical director of the unit, because he was the chief of medicine and 5B was a medical unit. But in the formal sense of the word, there wasn't an identified medical director.

And it didn't really become an issue the first year or two. Nobody ever really argued about it. But as the unit got more and more popular, and more and more acceptance, people did begin to question why there wasn't a medical director. It was one of those things that I was pretty emphatic about: "As long as I'm here, there's not going to be a medical director. This is a nursing model, and that's all there is to it."

Role of the Medical Staff

- Morrison: Now, when I left, there was. I was very pleased with how that transition happened, because I think the first medical directors on what was then 5A¹ were physicians that were within the hospital and in the clinic.
- Hughes: Michael Clement was the first?
- Morrison: I think he was the first medical director of 5A. He was ideal. He was one of those physicians that got his training there. We trained a lot of AIDS docs, and we were very proud of it. I look at them now, and I have a sense of pride. I think a lot of us do. Lisa Capaldini is a perfect example. I dearly love Lisa Capaldini. She was a resident during that time. She was absolutely wonderful to work with. She was somebody that you didn't have to teach too much. She was a great teacher for us as well. We loved her, and she was so easy to work with.

So yes, there was a lot of informal teaching. In fact, Merle Sande said that he liked to have all of his docs rotate through 5B and later 5A, so that they got that interdisciplinary experience. They identified that this psychosocial emphasis was something they weren't getting in their medical training, looking at the patient as a whole person, and the patient as being the center.

Hughes: So most physicians did appreciate that training?

¹ 5B was expanded and moved in 1986 and renamed 5A.

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- Morrison: Oh, yes, and I think because they saw the need for it in AIDS. I think medicine, maybe even nursing to a great extent at that point, still saw the whole AIDS thing as very isolated. The perception was it didn't really have application to any other area of health care. I always said from the beginning that everything that I was doing, and the nursing model that was created, were very relevant and very applicable to everything, not just AIDS care. I was criticized a lot for: "You're guilty of developing a secondary level of care and saying that some patients deserve better care than others." I was always quick to say, "No. I want to see all patients cared for under the same model that we're using with these patients." And I still believe that.
- Hughes: Well, define what the role of the physician was in those years when you were clinical nurse specialist in 5B.
- Morrison: In 5B and then 5A. Well, certainly the physicians were very important. They were head of their medical teams. San Francisco General is a teaching hospital. The difference was that physicians were never permanently on the AIDS unit, or any other medical unit at San Francisco General. They all rotated through. So there was constant change. Are you aware of how it's structured there?
- Hughes: No, I'd like you to tell me.
- Morrison: You have the medical staff, who are faculty at UC, and they all rotate taking turns doing their clinical stuff. They usually do it for a month, and they're assigned a team. They're the head of the team; they're the faculty. Then they will have a resident, an intern, a medical student, and there may be a couple of other people, maybe a pharmacy person or could be nutritionist, could be whatever. And for that month, they're assigned a certain number of patients, usually randomly as they're admitted.

So they would come through the AIDS unit. There would be all these little teams coming through. We, the nurses, coordinated the patients' care. Otherwise, the coordination piece was missing on the inpatient side, because the physicians were constantly rotating, and there was really no way for any one of them to deal with all of the issues and to make sure that there was some continuity of care.

So there really wasn't the "traditional" identified role for a physician. There could have been very easily, but because it was a small unit--in the beginning, 5B was only twelve beds--it wasn't really an identified need at that point to have a medical director.

A medical director on a unit has that unit as his primary responsibility. He works with the head nurse of that unit, and he's responsible for the medical care; she's responsible for the nursing care; they collaborate. And those aren't always the best of relationships. Sometimes they are. And because it's part of that old, traditional, hierarchical role, it's pretty much accepted that the medical director is going to be a male, the head nurse is going to be a female, and the physician is going to be in charge.

Morrison's Holistic View of Nursing

Morrison: We literally turned everything upside down and were looking at it from a more holistic point of view. I don't even believe in the role of head nurse. People will refer to me all the time as the original head nurse. I've never been a head nurse, don't want to be a head nurse. That's an old-fashioned traditional role that nurses want. They want somebody to be identified as being solely in charge. I was a clinical nurse specialist who was the clinical coordinator.

> One of the things that I did in choosing staff was I talked to them about problem solving, and about how they dealt with difficulties and interpersonal issues when they came up. One of the things that I said to everybody as part of the process: "This is an all-professional staff. There's not going to be a head nurse. I am the clinical coordinator. We will make decisions together, because we are a professional group.

"I also have an expectation that because you are all professional registered nurses, that you will behave as professionals. If you have a disagreement with another nurse, the first thing you do is you try to work it out with that person. If you can't, you let me know about it; we'll work it out as a group. But I am not going to play the traditional role of everything coming to me and I'm going to be your mommy, and I'm going to solve all your problems. Okay? I'm not going to make out schedules for all of you. We're going to sit down and make out the schedules together, and there will be equity."

Everybody loved that idea. It was like, "Wow, this is great!" Well, in practice, it didn't always work out that way. The staff used to get really, really mad at me, because they were used to this traditional setting where, when there were conflicts, you went to mama, the head nurse. She said, "This is what you're going to do." Mama solves the issues and that's it. I didn't do that, and the staff saw that as a weakness, and they didn't like it. Some people realized what I was trying to do and others didn't. In reality, they didn't like that, because in nursing, as I think in a lot of other professions, people don't like confrontation. They don't want to have to sit down and work something out with another person. I used to really push that.

I also identified early on that we needed not only a lot of regular meetings, but they also needed a support mechanism, but I wanted them to have control of that piece. The staff was given a lot of autonomy and independence, with an expectation that they perform at a very high level, and some people were not able to do it.

- Hughes: And then what happened?
- Morrison: They all stayed. When I left in 1986, all the original staff was still there, I think. Some people adapted to it better than others, and I think even the ones who disagreed, stayed for a lot of different reasons. It was very hard work, but it was very gratifying.

The Shanti Project

- Hughes: Well, talk about the conferences and the support systems that were put in place.
- Morrison: Well, I decided we needed to have psychosocial support. The nurses were going to be busy taking care of the physical needs of patients, and I wanted them to have an ability to recognize and deal with the psychosocial issues. But they were not going to be able to handle all of that.

Integrating Shanti Counseling into 5B

Morrison: So that's where I thought, Oh, the logical solution here is to bring Shanti in [to 5B], which had never been done before, because the politics was getting pretty thick at that point. I realized that if I made the proposal for Shanti to come in, it would never fly. So I took advantage of what was happening in the community, went to the then-director of Shanti [James Geary] and said, "Let me tell you exactly what you need to put into a proposal. You take it to Dr. Silverman in the Department of Public Health; I will tip him off, and let's see what happens."

Hughes: Now, why did you think that you shouldn't initiate that?

- Morrison: Because I was already getting criticized for being too powerful and too pushy. There was already this rumbling that I was creating my own little dynasty. And I didn't want that. I was very much focused on, This is what needs to be done. It didn't really matter to me if somebody else got the credit for it.
- Hughes: So you already had your lines established with Mervyn Silverman?
- Morrison: Oh, yes, almost from day one.
- Hughes: Because you were a nursing unit, and hence affiliated with the health department?
- Morrison: Yes, I was under the Department of Health and affiliated with UCSF. And even before the unit was open, Merv used to come to Merle Sande's meetings. He didn't come to the infection control meetings, but oftentimes he would come to Merle's meetings, because he wanted to know what was going on. And then he chaired his own meeting of the AIDS coordinating committee downtown, and I was a member of that as well. So I got used to communicating with him. I knew that he was a kindred spirit, and that he was somebody that I could trust and depend on.
- Hughes: Well, tell me about the evolution of the Shanti idea.
- Morrison: Yes, so the director of Shanti wrote the proposal basically as I outlined.
- Hughes: Was that Geary?
- Morrison: Yes, Jim Geary. I didn't always agree with him, but I agreed with Shanti, and that's where I came from. I always tried to leave personalities out, and I was better at it then than I think that I was later. People were like, "Oh, Jim Geary's an autocrat." And I was like, "Jim Geary is not the issue here. There's a bigger issue." So it didn't really matter to me, not at that point.

But yes, it flew. We got the funding for it. You see, the reason why I wanted it to be outside of me was because I knew the hospital was going to have a fit about it, and sure enough, they did. Geoff Lang didn't like it, neither did most other administrative staff, including nursing administration.

Hughes: Why?

Morrison: Well, he didn't like it because all the department heads were saying, "What kind of a hare-brained idea is this? You've got an organization [Shanti] that's pretty much gay-identified, and you're giving them a lot of access and a lot of power here. They're going to actually be working up here on this unit. They're going to have an office. Nobody asked for our input." I never, purposely never, discussed it with Dr. Sande or with other people, because I knew that there wasn't an awareness of what those issues were, and they would have never, ever accepted Shanti. I also knew that the powers that be within the hospital wouldn't.

Opposition

- Morrison: At that point, I was already at war with almost all department heads. They were all fighting me right and left. And that's where Merv Silverman came to the rescue.
- Hughes: Was that a turf-and-power issue?
- Morrison: Oh, everything. They resented everything. I had to fight associate administrators, department heads, people that were responsible for the housekeeping department, people that were responsible for laundry, the dietary service, you name it. They resented it because they saw that we were developing this program to ensure that there was a system of care for these patients, but in essence, we were telling them what to do. They wanted to be able to not serve these patients, and I was saying, "You can't do that."

It was Dr. Silverman who said, "Cliff, whatever you need, you do it. I've told Geoff Lang that all the department heads are to cooperate with you. If they don't, let me know and I'll take care of it."

Hughes: Now, that becomes another issue of the infection control committee, right? And Dr. Sande's committee?

Morrison: A lot of the dietary, linen, all that stuff [problems] got worked out through the infection control committee.

Debate over the Right to Refuse AIDS Patient Care

- Hughes: There had also been a decision that there was no reason for a health professional not to care for an AIDS patient.
- Morrison: Sure.
- Hughes: That, apparently, was a very controversial decision.
- Morrison: Oh, yes.
- Hughes: Was that Sande's committee's decision?
- Morrison: It was infection control's. I think Dr. Sande's committee supported it and gave it a lot more validity, because that was a bigger and more encompassing group. The infection control committee was already being criticized as, "The infection control committee is rubber-stamping whatever it is that Paul Volberding, Cliff Morrison, and Grace Lusby want."
- Hughes: Wasn't there controversy within the infection control committee?
- Morrison: Oh, there was. The majority of people on the infection control committee were very, very supportive, by and large, and thank god it worked out that way. There was a minority, and some were nurses, that didn't like what was going on at all.
- Hughes: Because they felt personally threatened?
- Morrison: They felt personally threatened--it's so hard to explain. An older woman who had been there for a long time was head of nursing education. We were in a meeting, and I was giving them an update on where we were at with the planning of this unit and getting it opened. I remember she was like, [huffing].

And at one point, she just kind of exploded, "Oh, I'm sick and tired of hearing about this! It's so distasteful, it's such a mess, and it's all your fault. You brought AIDS to this hospital. Why don't you just take it and go somewhere else, and leave the rest of us alone? You're ruining everything." That was the context of it. I remember [gasping]. Later on she came back to me and she was like, "Oh, I didn't exactly mean it that way."

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- Morrison: She was the only person that said it, but a lot of people thought it. Health care and nursing and medicine, we talk about change and being flexible and all this, but we're not. We're some of the people most resistant people to change that you will ever meet.
- Hughes: Please comment on the decision that if you were a health care professional, AIDS patients were part of your responsibility?
- Morrison: There were a lot of discussions. At the infection control committee, the discussion was basic. The philosophical discussions around it occurred at Dr. Sande's meetings, and there were people like myself, Dr. Wofsy, Grace Lusby, and other people who kept talking about, "Well, should staff have the right to refuse? Some doctors do." I had not realized until that point: doctors do have the right to refuse to care for patients. Nurses can't, and it's not a legal, it's an ethical issue. We all take an oath. The nursing oath basically says, "We don't have the right to choose our patients. Anybody that is under our care, we have to treat with the same degree of respect, and we don't have the right to refuse to provide care to them."
- Hughes: Doesn't the Hippocratic Oath say the same thing?
- Morrison: In a different way, but there's an out for doctors. At one of those meetings Dr. Sande said, "You mean nurses can't refuse to care for a patient?" I said, "No, they can't." It was Grace and I who really emphasized that. Oh, it became a really big issue, and was tested a lot. [laughter] It was also a national issue, but it was being played out at San Francisco General for sure.

SFGH/UCSF Infection Control Guidelines

Prototype

Hughes: When the infection control guidelines became available on a wide scale, namely, I'm presuming, through the <u>New England</u> <u>Journal</u> article, did they serve as the prototype for infection control in AIDS medicine?

- Morrison: That first article? Yes, I think it was. That was kind of the blueprint. I think that was the first time in any of the professional literature that anything like that had ever appeared. Because the list of names that followed it was unbelievable--with the exception of mine. That was the first time that any of us had ever seen anything like that. There had never been that kind of universal input and consensusbuilding on a particular issue.
- Hughes: Did those guidelines also influence CDC policy?
- Morrison: There has been discussion, and I've heard this off and on, about who influenced whom and who came first. I think they were being developed pretty much parallel. They influenced each other greatly. We'd have Dr. Curran come in, and he would tell us what he thought. But at the same time, it was obvious to me and to, I think, everybody else that CDC was looking very closely at what we were doing. Paul and Merle and all these other people were going back to the CDC on a regular basis. I wasn't at that point; I was still staying pretty much institutional.

CDC Guidelines

- Hughes: Well, CDC did come out with some guidelines at the end of 1982.¹ But as I remember, they're very--
- Morrison: Vague.
- Hughes: Were they lifted from the hepatitis B model?
- Morrison: They were.
- Hughes: They were not formulated on the basis of experience with infection control in AIDS. Am I right?
- Morrison: Yes, I think you are right, because we didn't have the clinical experience to draw on. We knew that the hepatitis B model, particularly for infection control, was what we needed to do. And that was CDC's contribution, I'm pretty sure. They identified that early on.

¹ CDC. Acquired immune deficiency syndrome (AIDS): Precautions for clinical and laboratory staffs. <u>Morbidity and Mortality Weekly Report</u> 1982, 31, #43: 577-579.

Hughes: The hepatitis B.

- Morrison: Yes.
- Hughes: The hepatitis B vaccine trials were going on, so hepatitis B presumably was on their minds.
- Morrison: Oh, yes, it was. Yes, here you have this whole new disease that nobody knew what to do with, so you had to have something to build on. There was this need to turn to hepatitis B because it was there, but luckily, it fit. [laughter] I mean, it really did, and it's still pretty much the basis for how we deal with things today.

Ward 5B (Continued)

[Interview 3: January 30, 1996] ##

Criteria for Admitting Patients

- Hughes: Cliff, were there criteria for patient admission to 5B?
- Morrison: Yes, there were. We knew, if not by the time 5B opened, within a short period of time, that the twelve beds that were there were probably not going to be adequate. So what we decided to do was, as patients were admitted, we would prioritize them. The sickest would be the ones that we would try to get to 5B. That was pretty much the way we did it in the beginning. Actually, it's pretty much the way things go now at San Francisco General.

And sickest doesn't necessarily mean physical. If we identified a patient that was out on one of the other units that maybe had a case of *Pneumocystis* that was going to be manageable, but had a lot of support needs or psychosocial issues, we considered that as part of the criteria for admission to 5B.

Hughes: So it was a very holistic assessment.

Morrison: Yes, it was.

Hughes: Now, that meant that you or somebody from 5B was circulating through other wards?

Morrison: Yes.

- Hughes: So in a sense, you were responsible for every AIDS patient, regardless of his or her location?
- Morrison: Yes. Maybe for the first two or three months of the unit, we were able to keep all the patients on 5B. In fact, right after the unit opened, we'd been averaging ten to twelve patients a day, and then all of a sudden, it dropped. There was even some joking among us like, "Do we really need this unit now?" I think the first week, we had four, six patients, something like that. It took us the first month before we actually wound up with the unit being full. That alarmed some people.

Staff Education

Morrison: I was actually kind of glad, because it gave us an opportunity to work out some of the kinks, although each of the nursing staff had gone through an intensive orientation process the week before the unit opened. I set up this pretty rigid curriculum, and for a solid week, the staff on 5B went through nutrition, we went through updates on all of the drugs, what was happening in drug therapy. I had Connie Wofsy and Donald Abrams come over and discuss the immune system and other aspects of AIDS.

> We had very structured classes for a whole week, and we covered everything. We spent a whole day just dealing with psychosocial issues, and had people from different groups in the community. It was already decided that Shanti was going to be there, so at that point we brought them in as well. We began to talk about how that relationship was going to work and who would be doing what, because we knew that there were going to be some problems that would arise, because we were doing something that hadn't been done before.

Hughes: Now, was a holistic training usual in nursing?

Morrison: It was. Nursing has always been very good about educational programs and having good, solid orientations. So from the beginning, Maryanne McGuire and I had decided that as the nurses were hired--and most of them came from within the hospital or the San Francisco Department of Public Health system--we would put them on the couple of medical units where we had a lot of AIDS patients, and start orienting them to the physical and nursing needs and the medical aspects.

> Also I was meeting on a regular basis with each of the staff as they came on 5B, identifying what the areas were that

they needed to learn, so that each nurse knew what it was that they needed to work on.

The Concept of Primary Nursing

Hughes: Now, Cliff, where was your information coming from?

Morrison: It was from a combination of sources. I mentioned before that primary nursing had been around for over a decade. Everybody had always liked the idea of primary nursing, but it wasn't cost-effective. R.N.'s cost more money, and is it costeffective to have just R.N.'s providing the total care when there are other aspects of the care that less educated, less trained people could do?

> One of the things that I talked to staff about when they were all interviewed was the concept of primary nursing--how did they feel about doing total care? And it was interesting that they all agreed with it. But yet when we actually started practicing it, there were some real problems with it.

> I did some literature searches on primary nursing, so it was a combination of what was already there and some of my own personal philosophy. People liked the idea, but then when we started practicing it, the first thing they started complaining about was, "Well, I'm not used to making beds. I'm not used to emptying bedpans. I'm not used to doing all this scut work that we've always had orderlies or somebody else to do." Well, we had two orderly trainees that came on, so they did a lot of that. But the staff was like, "Well, maybe we do need one orderly or somebody around," and I'm like, "No. You do everything."

Hughes: What is the principle?

Morrison: The principle actually went a step further for me than what I found in the literature pertaining to primary nursing. At that time, case management wasn't a term that we were totally familiar with, but I was familiar with the concept. And essentially, I saw each of the nurses not only as being a primary care provider, but also being a case manager, essentially coordinating the care for that patient.

> I ran into a lot of trouble with that too. Again, it was one of those things that when we went through orientation and we talked about it, it made a lot of sense. We even put a big board up in the front of the unit where we could say, when

patients came in, they were assigned to a primary nurse. I tried to get across to the staff the importance of, "You're going to coordinate every aspect of this patient's care. The primary nurse will be responsible for setting up the care plan, for coordinating with the physicians, coordinating the medical care, coordinating the psychosocial needs, immediate preparation for what kind of a disposition is going to be needed for this patient." So that we could plan everything and have one nurse that would be responsible for it.

Of course, the patients were there twenty-four hours a day, but the nursing staff was working twelve-hour shifts. That's something that we voted on; the nursing staff wanted to do that. So of course, with that setup, it meant that patients wouldn't have the same nurse caring for them every day, but they would have one nurse that they knew was coordinating their care.

Again, this was one of those things that sounded really good to talk about. In practice, it didn't work that way. Again, because everybody was individual. Some nurses were very possessive and liked the idea of having that kind of a relationship and that kind of responsibility. Within a short period of time, I found some nurses saying, "I don't want to care for this patient every day, because I don't necessarily like him." Or, "The level of care is so intense that I need a little bit more variety."

I had set up ratios for care. The hospital was in the process of going to a system whereby we used very objective--or as objective as they could be--criteria to figure out staffing ratios based on acuity. It was called an acuity scale, acuity levels. And so we implemented that.

Now, the difference was that 5B was the first unit in the hospital that wasn't a critical care unit where the ratios of nurse to patients were lower. I was emphatic on the day shift, which was from seven a.m. until seven-thirty p.m., that R.N.'s cared for no more than three patients. And then on the night shift, the ratio would be one to four, because there's less going on.

Hughes: And there was argument about that?

Morrison: Oh, yes.

Hughes: Because it was costly?

Morrison: Yes, it was costly.

Hughes: But surely even administrators must balance cost versus need.

- Morrison: Yes, and quality of care. Interestingly enough, they were pretty good about it. It did take some arguing, but we presented the arguments. The medical staff supported it. This was one of those occasions where Dr. Sande stepped in and said, "Yes." I don't think he really understood exactly at that point. I think he did later on. Not only were we learning a lot about working with physicians, because the relationships were different, but I think the physicians that were involved were learning a lot about nursing.
- Hughes: Dr. Sande hadn't actually cared for AIDS patients himself? Because if he had, would it not have been apparent to him that they required more intensive nursing care?
- Morrison: Actually, I think he did understand that, and pretty early on, because he did his normal rotation through the units. He would come around with the medical teams, so he saw how sick these patients were. In fact, we used to talk about the fact, "Wow, you get a patient with AIDS, and every system is involved." From a training standpoint, it was overwhelming for a medical student, an intern, or a resident, because they had everything at once.

But on the other side, we all recognized that not only for the medical training programs but also for the nursing training programs, AIDS was almost the ideal teaching situation. Yes, it was overwhelming, but for the first time, we were having a significant number of patients where you weren't looking at just one aspect or one system within the body; you were looking at everything. And patients always had multiple problems. We'd never seen patients receiving all these different medications before. It was just an enormous number of pills and IV's--it was staggering.

Setting Up 5B to Facilitate AIDS Care

Morrison: Almost as soon as the unit opened, we really began to see the benefits of having it. I had said before that one of the benefits would be that it would give us an opportunity to not only coordinate care better from every level, but also that it would be easier for the medical staff because they would know where their patients were. Patients would have a staff that was very knowledgeable and up to date on all of these issues, so that when they came on the unit, they didn't have to look around to find somebody who knew something. In setting up the unit, we tried to make it as easy as possible in terms of supplies, where things were located, and to order the things that we knew that we were going to be using a lot, so that we didn't have to waste time running down to central supply to get stuff. One of the first things that the house staff, the medical staff, recognized and complimented 5B on was that we were not only the best-staffed unit of the medical units, but we had also recognized what was needed there so you didn't have to run around all over the place searching for it.

- Hughes: When you say "best-staffed", do you mean in terms of expertise?
- Morrison: Expertise in dealing with this specific diagnosis, and also because the staffing ratios were better. You go to a regular medical unit, and you might have one nurse caring for seven, eight, ten patients. So nurses had less time for each patient, and they were caring for a wider variety and range of patients.

5B as a Model Nursing Unit

- Hughes: On the other hand, Cliff, did this fuel the argument that AIDS was taking too many resources?
- Morrison: It was taking too many resources. Almost from the beginning, there were accusations that we were setting up a two-tiered system, that we had talked about how these patients had been discriminated against before, but now we were discriminating against other patients, because we had created a level of care that was actually higher than the rest of the hospital.

My reply always was, "We see where you're coming from. However, the needs of these patients are great, and what we're hoping is to be able to use this unit as a laboratory. Because of the way it's set up, we can experiment with things. Hopefully, what we're doing here, we will be able eventually to integrate into other units in the future, so that the care of all the patients will get better as well. We can learn from this."

Hughes: Well, one of the themes of your articles is that AIDS has exposed the deficiencies in health care delivery, but we can use AIDS care as a model that might have wide implications.¹

¹ See, for example: Cliff Morrison. "Nursing perspectives in the care of patients with AIDS," op. cit.

- Morrison: Exactly. In fact, I think that was my original point of view. I didn't think AIDS was going to be around long. And I don't think anybody else did either. We thought that the door would open within a few months, and that we'd solve this, and it would be over. I think I recognized within a few months that wasn't going to happen.
- Hughes: What made you think that maybe this was a long-term problem?
- Morrison: Because once it got really cranked up and the system was functioning smoothly, it's like there was this rush of patients then, and they were coming from everywhere. And there weren't the big medical breakthroughs that we thought would come. We were getting better at the treatment, and the patients were living longer.
- Hughes: After the isolation of the virus, people begin to think, Okay, we've got the virus, the vaccine and drugs are just around the corner.
- Morrison: Exactly. [laughs] Deals being made everywhere. All the politicking at every level.

Hospice

Morrison: I worked very closely with the hospice coordinator, Eileen Lemus, in the hospital, and I was a firm believer in and supporter of hospice care. There had been discussion for a long time that we needed a more formalized program at San Francisco General. We had a hospice coordinator, but we didn't have any inpatient hospice beds.

> We thought, Hey, this epidemic is not going to be more than a year or two. The model that we're setting up here in 5B is a combination of hospice care and oncology and critical care and primary nursing and all these different things coming together. Because of the size and the shape of the unit, well, we'll use it for AIDS for a couple of years, and then as AIDS disappears, we'll transition it into an inpatient hospice unit. That was the goal. That was what we set out to do.

In fact, from the beginning, we designated two beds that would always be for hospice patients, and for probably the first year or so, that pretty much was what we did. We did keep those beds. In fact, I think the first patient that died on 5B was a hospice patient, not an AIDS patient. It was a woman, I think. Diane [Jones] would know. I kept saying, "We need to be able to coordinate everything. This approach will give us an opportunity to centralize resources. At the same time, there's going to be some secondary gains and advantages to this in that we're going to wind up with a staff from a psychosocial standpoint, from a nursing standpoint, and from a medical standpoint, that are, quote, experts on HIV and all the related issues."

And almost from the beginning, we recognized--things Dr. Sande and I began to work together on--that, Hmm, all these AIDS patients aren't going to wind up on 5B. Some of them that may be admitted for something that really is not related to AIDS wouldn't necessarily have a need to be on the AIDS unit. But at the same time, we needed to connect with them in case they did get sicker. And in the beginning it was easy, because I could do that. But later on, we recognized that it was important to create a team.

Shanti

Morrison: We had three Shanti people. Linda Maxey was a registered nurse who had been at Shanti for a long time, and I had worked with Linda quite a bit. So the deal that I had made with Shanti was, "Let's do this proposal to the city. I'll support it, but under the condition that Linda Maxey is the coordinator for it, because she's a nurse and she'll understand all of this. It's really important that we have somebody like her to do this, because it's never been done before. If we don't have somebody coordinating it who understands how hospitals operate, then we're going to be in a lot of trouble."

> The concept and philosophy of Shanti was something that the community was already very proud of, but hospitals looked at it as like, This is not us; this is not what we do. And these people are basically in the way, and this is not our focus. So that was a smart move on our part, and it worked.

> So, yes, all those things did come together, and we did see the advantages right away of having these resources centralized. And almost immediately, what we found was that people from within the system--within the Department of Public Health, within the hospital, from other hospitals--started calling and coming to us and saying, "Oh, well, you've developed this approach to care, so how can we do it?" Almost everyone looked at our setup and said, "This is unique. You can do this here because it's San Francisco General. We can't duplicate it exactly."

Providing a Model for Nursing

Morrison Draws on his Education

- Morrison: Now, I had hoped from the beginning that 5B would be a model that really could be duplicated, and I still think that it easily could. But there was resistance--
- Hughes: You thought the model could be developed for AIDS, or even broader than that?
- Morrison: AIDS, and broader, yes. For me, it was an opportunity, because I had an understanding of primary nursing. This was the first time in my career that everything that I had done came together and made sense. Because by that point, I had already completed all of the education that I have now. A lot of people have wondered, Why did you wind up with a degree in hospital administration, and then go back and get a master's degree in nursing, and then one in education?

Well, the answer was that I wasn't sure. It's just that that's the way things happened. I got my first master's in health care administration because I began to think, Well, maybe I've outgrown nursing; maybe I want to do something else. Health care is certainly what I'm interested in, so I need to have a little broader perspective of it. When I was a lot younger, before I even had a degree, I recognized that one of the major deficiencies in nursing was that nurses really didn't have a sense of business. Here we had all this expertise and this need to be very organized, but yet, our educational curricula weren't geared toward management. The business aspect was just lost.

I've been a nurse now since 1971, so twenty-five years. I remember when I was in nursing school in the late sixties and early seventies I would ask questions, and people would say, "Nurses don't need to know this." At that point in time, the need for a nurse to understand health care policy issues was unheard of. Why would a nurse want to know? What input could they possibly have? That's not their domain. Leave that to hospital administrators and physicians who know better. Nurses are advocates for patients; they have nothing to do with policy.

From the very beginning, this didn't make any sense to me. I felt, god, if anybody should be involved in policy making, it should be nurses. We have an understanding of what people's needs are. I didn't ever really think that that would change, but certainly it was something that I thought about.

I had always seen this need to support the psychosocial needs of patients more. I think that we were doing a terrible job in acute care settings. We just didn't deal with those issues, unless a patient tried to commit suicide. Then we'd call in a psychiatric consult. And that was it. It was so rigid. Everything was so confined and isolated. The holistic approach just wasn't there in health care at that point in time.

So I had this master's degree, and then after I got it, I did some nursing management administration and felt like, god, this education was almost a waste; I'm not really using a lot of this. I came out of it with a little better understanding of the business aspects. Nurses used to get really upset with me when I would say things like, "You know, nurses really need to think more like business people. We need to have a sense of business about us, because nursing involves money; it involves budgets." If a nurse wants to move up beyond the bedside, it's important to have at least a working knowledge of some of these issues.

There wasn't a lot of acceptance within health care of that idea, and even within nursing, I don't think there was. I would hear nurses say, "We don't want to know about this stuff. We like it the way it is. We've got enough responsibility as it is; don't create any more responsibility for us."

But there was already the beginnings within the profession, because things were changing in health care, being driven by economic forces. In nursing, like a lot of other traditional professions, your leadership tends to be older, and it certainly was no different in the early seventies. So all of a sudden, you had a whole new generation of nurses that were coming in that were being trained and educated differently.

It's one of these things that people still laugh about, because I'm always correcting people: physicians still refer to their educational process as training. I was just fanatical about it: nurses aren't trained; nurses are educated. You train monkeys. You train dogs. Okay? You don't train people; you educate them.

I've heard Merv repeat that several times, and Dr. Sande as well. They thought it was a cute concept. They'd never heard it before. But then hearing it, it made sense. Training people means that you train somebody to do a task. And nursing had done a very good job of that for a long time. Hughes: Yes, and that's what you were trying to get away from.

Morrison: That's what we were trying to get away from. Nursing education changed; we had moved away from hospital-based nursing programs to nurses being educated in universities and colleges. And there are still arguments today: Who is the better nurse, the nurse that went through a diploma program that was hospitalbased, or a nurse that went through a college or university baccalaureate program? There are advantages to both. I think almost anybody will tell you that when it comes to just sheer task techniques, physical care, the best-prepared nurses are those that went through the diploma programs. They are technicians. They were trained. [laughs] Nobody can make a bed like a nurse from a diploma program. Their emphasis was that: the task.

> Whereas, for those of us who went through college and university programs, tasks were important, but they weren't the top priority. We were educated to start thinking, and to start looking at the patient as a whole person. So that's what I started doing.

Holistic Nursing

- Morrison: It became really obvious to me even before the unit was opened that one of the major problems we were having was that we didn't look at patients as whole people, that everybody was dealing with a body-system, or one aspect of care, but nobody was looking at the whole person. And yet, everybody was beginning to wonder why was there all this dissatisfaction? To me, it was relatively clear. This is the path that I took.
- Hughes: It was logical in your mind to have the nurse become the person who pulled it all together?
- Morrison: Well, yes. [laughs] This was the first thing that got me out on the circuit, where I started doing a lot of lecturing. There was a nurse [Joanne Powell] that worked at the Golden Gate Nurses Association who wanted to know more about what was going on with AIDS, and came and heard me speak one day at the hospital. She walked up to me afterwards and she said, "We need you out there promoting nursing. I've never heard anybody talk about nursing the way that you do, and it comes across. It's obvious that you're very committed and dedicated to this, and it makes sense. Nobody's been saying this before. Bits and pieces we've all thought about, but nobody's put it all together and put it out there quite that way."

One of the things that I start saying --

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Morrison: --You have to deal with the whole person, and we're also the only providers that are with the patient twenty-four hours a day. Physicians come in to deal with a symptom, to deal with a specific issue; they leave. Respiratory therapist comes in; they deal with a respiratory problem. A laboratory technician comes in, draws blood. X-ray comes in and takes an x-ray. They all come in with their different pieces, and there's nobody really looking at it as a whole and trying to balance it and meet the needs of the patients.

Patient-centered Care

Morrison: So that's when I began to talk about patient-centered care. Of course, that was a term that came from the literature, so it wasn't new; I didn't invent it. But it certainly was new at San Francisco General, and that's what I began to talk about. At the time the unit opened, people kept saying to me, "This all sounds really new," and I kept saying, even to reporters, "No, it's not. It's been in the literature. It's just maybe I'm one of the first people to pick it all up and put it together and see."

> AIDS did more than anything else in our lifetime to bring all of these issues together. We really did begin to see what we were doing wrong, what was inefficient, what was really lacking, all these gaps in care, the fact that we didn't really have a good connection to the community, that we weren't doing good discharge planning, that we were doing acute care. We were taking care of a symptom or a problem, and then they were discharging people, and then patients were coming right back because we didn't follow through. They got out there, and they didn't have any support, and they deteriorated, and they were right back.

The Oncology Model

Hughes: Paul Volberding talks about an oncology model in sort of the way that you talk about a primary nursing model.

Morrison: Yes, that's true.

- Morrison: It did.
- Hughes: Neither of you were creating it completely de novo. But I guess I would like you to clarify how those two concepts interrelate. When he talks about an oncology model, is he talking primarily about the medical team?
- Morrison: Yes. Because his orientation is the medical model. I'm an observer looking at what's happening in nursing, but I'm also observing what's happening in medical education as well. The roles of physicians are changing. Roles for nurses are changing as well. Not all of us are totally comfortable with it, and there's some good and there's some bad to it.

The oncology model is certainly one that I very quickly went to, read everything I could on it, pulled out what I saw as good. I have probably pulled more out of hospice for nursing, because hospice was much closer to a nursing model, although it really wasn't either. Because there wasn't acceptance of hospice in this country. I'm not sure there still is, but certainly fifteen years ago, there wasn't a lot.

But yes, the oncology model that Paul was referring to was a medical model. He did see the multidisciplinary need. He understood the importance of having other disciplines involved, social work and nursing. But he still saw it from the medical model perspective. So we agreed on that much. I saw it not so much from a nursing perspective; I just saw it as more holistic.

We're talking about control, at every single level. But the single biggest issue of control is control of the patients. If you do patient-centered care, then control goes back to the patient, and the patient becomes a partner in the decisionmaking. You educate patients from the time they come in; you start working with them; you give them all the information that they want; you let them be in the driver's seat, and they dictate what's going to happen. The control is in their lap.

We know now that those are the patients that do the best. They're also the patients that can be the most difficult to deal with, because they're demanding. That created problems that we'd never had before. Physicians didn't like it; a lot of the nurses didn't either. They just weren't used to patients challenging them, and it was the first time that most of us had ever seen patients that knew more about their medications than we did. Patients were coming in and bringing articles. I mean, they were up to date. Again, I'd had a little bit of precedence in that area, because I'd worked in psychiatry, and psychiatric patients are usually pretty good about knowing their medication. They're not pushy about care, but they do know all their medication. They can rattle it off and tell you exactly what the side effects are. So I had had that experience.

- Hughes: Patient-centered care was a challenge to the power structure of medicine and nursing, wasn't it?
- Morrison: Yes, it was touching on everything. And besides that, you had all of these different things going on at the same time, and on top of it all was this overlay of bureaucracy that I think still dictates a lot of it. I still think control is on top. We had never had to deal with young people dying before our eyes like this, and the numbers. It was bringing up all of these issues that had been there, but nobody would deal with.

Dealing with Death and Dying

Morrison: There were a couple of things that I used as anecdotes to get my points across, and one was that we had never really dealt with the issues of death and dying very well. I'd had experience as a staff nurse of being assigned a woman who had breast cancer and was dying, and being told, "Oh, you can have Miss Jones; she's down at the end of the hall. She's terminal, so she doesn't need much care."

> Going down to Miss Jones's room, I found that the shutters were pulled; it was dark; maybe somebody was with her, maybe they weren't. But nobody was talking to her; nobody was meeting her needs. We weren't looking at pain management quite that way. Hospice was already looking at pain management.

> I remember saying to a supervisor once, "You're giving me all these dying patients and telling me that I have the lightest load. I don't have the lightest load. These patients need more than all of the other patients combined," and not getting anywhere in nursing by saying that. Physicians were also not dealing with it, because the worst thing in the world that can happen to a physician is to have a patient die on them.

So it began to crystallize for me at that point: the reason why we're constantly at odds with each other is the medical model and physicians' focus on cure. Nursing focuses on care. Cure is something that nurses can embrace, but that's not what we're there for. We're not the curers; we're the carers. So there's always a role for us, and it's clear to a nurse when we put it in that perspective. It's harder for physicians to understand that, I think.

As a result of this, in all these different meetings, we would have dialogue about these very issues. And I think that that was one of the most beneficial things that happened. Particularly in Merle Sande's group, we discussed that stuff a lot. And I was always surprised that we did have that level of discussion there. It was pretty remarkable.

At the same time, it was kind of heady, too. We were talking about a lot of ideal things, and then trying to implement them. Everybody was wondering, Have we lost it? Have we gone completely over the edge? What are we doing here? Does any of this make sense?

At the same time, it was also creating problems within the institution and within the community, because people were looking at it and not understanding it. I was being accused of advocating for this group of patients at the expense of other patients, and that we were creating this special care unit only for AIDS patients. In fact, the original title for 5B was Special Care Unit. I dropped "Special" and just started calling it the Care Unit. Because the whole idea of special, I think, created a gap and a barrier. I think to this day, it's still there.

- Hughes: But the very nature of AIDS medicine and AIDS nursing, because they are so comprehensive, differentiates them from other types of nursing and medicine.
- Morrison: Yes.
- Hughes: Yet, I can see the problem of setting up a special unit. It plays on all kinds of things.
- Morrison: Oh, it does. We were calling it the Medical Special Care Unit. So we dropped the "Medical" and the "Special." We started dealing with the death and dying issues, which were enormous and difficult for everybody, nurses as well; but I think nurses were a little more used to it than physicians. We were the ones that were generally with the patients when they died.

Dealing with Sexuality

Morrison:

n: But then the whole issue of sexuality--boy! Now, that's really what had people coming out of the woodwork. I mean, people would lose it over that. You could see anger, and pounding their fist on the table, and "This is ridiculous; this doesn't make any sense at all." Again, it was one of those things that I was preaching from an anecdotal experience. I had been working in a critical care unit a few years before, and I had been taking care of this man in his late fifties. He'd had an MI, myocardial infarction--major heart attack. He was released from the ICU and went to a transitional care unit, and then we were getting him ready to go home.

Well, at that point, in nursing and medicine, we were already making a big deal about how we were educating patients. I saw this patient getting really agitated. I had mentioned it to the doctor, and the doctor was like, "Well, it is not uncommon to see reactions like this." Well, here was obviously a very heterosexual, virile man, and I was like, "You're obviously upset about something." Well, he'd glare at me and say, "It's nothing that you can help me with."

Within twenty-four hours, this patient was going to go home. I came in his room one morning, and he was really angry; he was all but yelling at me about how inefficient we were, and how we didn't meet people's needs, and all he wanted to do was get away from here, that we always thought we knew best. I was like, Okay, I've got nothing to lose. Here's an irate patient who, if we're not careful, is going to have another heart attack.

I said, "I want to be able to help you, but I don't know what to do." And he was like, "Can't somebody around here just answer a simple question?" And I said, "What's the question?" And he said, "I'm going home, and nobody has told me, can I have sex with my wife without having to worry about dying while I'm on top of her?" And he said it just like that.

I remember the blood just draining from me, and I stood there and I looked at him, and he was like, "See?" And I was like, "I don't know. I never thought about it. Let me go talk to some people, and I'll find out. We'll get an answer for you." I think the physician caring for this patient was somebody that was pretty thoughtful, and I called him and I said, "This is what he wants to know." He chuckled, and he was like, "You know, it comes up a lot. Patients want to know this stuff. This is not our role." And I got to thinking. "It's not our role." Isn't it interesting? At that point, we didn't even really take sexual histories on patients. One of the things Lisa Capaldini and a few other people did was that they began to focus on, when patients come in, within twenty-four hours, the medical staff has to do a physical exam and an assessment. Nursing is supposed to as well.

Nursing skirted the whole sexual aspect. Sometimes, we might note if somebody was homosexual, but that was really it. So I began to notice then, there's a whole issue about sexuality here that we've just completely ignored. Sexuality is as much a part of a person as breathing and eating. So there's got to be a way to do this.

When I was in Miami, here I was, still a person kind of in and out of the closet, and I wasn't really sure that I wanted to make an issue out of sexuality, because then people would start looking at me and saying, "Why are you making this an issue?" When I got to San Francisco General, it was a little easier, but still, people kind of pooh-poohed it.

So AIDS was the first thing that I noticed--and I think that most of the doctors felt the same way--where sexuality really did become a major issue. The problem with it was that it would have been bad enough if we were dealing with sexuality, period; if we were dealing with a heterosexual population. But we were dealing with a gay or homosexual population that none of us had ever discussed openly. There were "secrets" in the gay community that were considered taboo to discuss in front of others. As with every minority group that feels disenfranchised, there are things about our cultures that we keep to ourselves. We all have our little dark secrets.

In the gay subculture, that dark secret was bathhouses and a lot of sexual practices. Gay people did not talk to straight people about bathhouses. We didn't talk to straight people about what kind of actual behaviors we practiced. That was taboo. Now, all of a sudden, there was a need to do it, and it was interesting to see how people responded to it. Two people I always think of right away are Selma Dritz and Grace Lusby. It just rolled right off of Selma.

Hughes: Which may have something to do with her experience in the field of sexually transmitted diseases.

Morrison: Exactly. She was used to discussing it. It was no big deal to her. I think for a lot of us, it was almost voyeuristic. I was embarrassed personally at some of the stuff. They were talking about practices that I'd never heard of, and that certainly I'd never practiced, and then there was the assumption that we all did this. There were a lot of assumptions at that point in time about gay people and gay lifestyles. Straight people assumed that all gay people did the same things and didn't understand that there was diversity within the subculture, particularly that not all gay people were sexually active. Some of us barely had sex lives.

Ward 5B (Continued)

Staff Meetings and Conferences

- Hughes: Well, let's go back to 5B. What staff meetings and conferences were set up, and for what reasons?
- Morrison: There were a lot. We have always been criticized in health care for having too many meetings. Well, one of the things I've learned is, you can't have too many. But you need to make them all very goal-oriented. You don't have a meeting for the sake of having a meeting. I've worked in psychiatry; psychiatry has always been criticized, because we'd spend our whole day in meetings and never take care of patients. We'd discuss what we were going to do with patients, but then never have time to do it. I could understand the criticism. In the beginning, that was also beginning to happen some with AIDS, except that the needs of patients were so great that it pushed us out, so we really did have to start looking at these meetings and setting priorities.

Discharge Planning

- Morrison: On the unit, one of the first things that we set up was a discharge planning meeting. That's where Jeannee Parker Martin came in.¹ She started coming from Visiting Nurses [Association] and Hospice [of San Francisco], and we would have this meeting every week, I think it was on Friday morning, in our conference room on the unit.
- Hughes: Now, was discharge planning a new concept?

¹ See Martin's oral history in this series.

- Morrison: Yes. Well, there were discussions about it. It had also been in the literature, that we needed to start looking at discharge planning and dispositions. But in actual practice? There was actually at that point in time [1983-84], I think, a discharge planning committee at San Francisco General.
- Hughes: Associated with AIDS?
- Morrison: No. But we weren't really doing any discharge planning, or very little of it.
- Hughes: [laughs] Just having meetings.
- Morrison: Yes. And there were plans to do something with it, because the accrediting agencies were now calling for it. But all of a sudden, we had a group of patients that were forcing us to do it, so we took it to the next logical step.
- Hughes: Were the organizations calling for it primarily because they saw it as a means to reduce hospital costs?
- Morrison: Yes. It was becoming increasingly clear that the cost of health care at that period was escalating. Inflation was pretty high during that point in time, but health care was like double what the inflation rate was. Well, it's more than that now; we're running 10 to 12 percent, when inflation's only 2 to 3 percent. So yes, somebody somewhere along the way from a business perspective had begun to realize that we need to keep patients out of the hospital. What's the most logical way? You start looking at what you're doing in the community. Which I think was good. I think the shame of it is that at that point, we weren't looking at prevention the way that we should--still aren't. But I think we're slowly beginning to pay attention to this.

A number of people over the years have disagreed with me about this, but during that period [1983-84], particularly at San Francisco General and maybe even in the state, I think AIDS began to drive health care. I think today, it does. I still think that there's a reluctance to admit that. AIDS has become such a big issue because it crystallized all these issues so clearly, that for the first time we really did begin to pay attention to, How much is this costing us?

Case Management

Morrison: On the one hand, that was good. What I don't like about it is I think that we still continue to focus on the cost at the expense of quality. Now, everybody will throw "quality" around in a minute, and they'll talk about all this stuff. I've written several articles on case management.¹ I'm a purist; I believe in case management the way that it was originally conceived, and that you have to have very clear goals. The first goal of case management is that you do it because you want to create an atmosphere where you can deliver the highest quality of care possible. Your last goal will be that you want to do it in the most cost-efficient manner as possible, but not at the expense of quality.

> Well, people have latched on to the idea of discharge planning, case management, and all these other superfluous terms, mainly to be able to reduce cost. There's also a lot of confusion, because we never defined case management, and a lot of people think discharge planning is case management. It's not. Discharge planning is only a component of case management. I go to case management meetings and say that, and people get upset with me, because there are now all these roles for nurses and non-nurses that are called case managers, and they're all doing different things. Some of them are nothing but discharge planners, but they're calling themselves case managers. So you can see that you've got to be careful in health care. You can step on somebody's toes really quick.

More on Discharge Planning

- Hughes: Yes, I can see that. Well, go back to the discharge planning meetings. Jeannee Parker Martin was there, but who else would attend those meetings?
- Morrison: We had a public health nurse that came from the public health department.
- Hughes: What was her function?

¹ See for example: C. Morrison. "Case management and the determination of appropriate care settings for persons living with AIDS." In: U.S. Department of Health and Human Services. <u>Community-based Care of</u> <u>Persons with AIDS: Developing a Research Agenda</u>. Washington, DC: USDHHS, April 1990, pp. 75-82.

- Morrison: Public health nursing in San Francisco is a little bit different, because I think we have a very good public health department. San Francisco always has. It spends more per capita than any other city in the country on public health. Public health nurses in this city tend to be more in a coordinating role. They identify what issues are out in the community; they do a lot of education. It was obvious to all of us that they knew what was out there. So they came in to provide that expertise and to look at how we could begin to structure things and realign them so that it made sense.
- Hughes: In other words, for a given patient who might need X, Y, Z services, then the public health nurse would say, "These are the resources available in the community?"
- Morrison: Yes. See, what we started doing on the unit was, when a patient would come in, I'd say, "Okay, we've got to have a plan for this patient within twenty-four hours, and from the first day this patient comes in, I want us to start talking about his discharge." He might be there fourteen days, or twenty-one days, or whatever. Why are we talking about discharging him the first day? Because we need to start planning, and see what this patient is going to need.

So every Friday morning, when we'd have this discharge planning meeting, the nurse that was coordinating the care for that patient would present the case, with the care plan. "Okay, for example, we've got this patient who has *Pneumocystis* pneumonia. It looks like we'll be able to treat it; he'll probably be discharged in three weeks. He doesn't have a home to go to. Or if he does, he only has a lover, and the lover doesn't have a medical background and works twelve hours a day." We began to look at it.

So the Shanti person, Jeannee Parker Martin from Visiting Nurses and Hospice, Eileen Lemus, who was the inpatient hospice coordinator, would come. Because for the first time, we began to make dispositions of these patients to hospice. Sometimes we would have a nutritionist that would come in. Anybody that wanted to, that could give us information about this case, we would bring those people in. We were trying to create an atmosphere on the unit where we could treat the patients, meet their needs, and get them out as quickly as possible, but at the same time, create something where they weren't just going out there into a vacuum.

Social Services

Hughes: Did hospital social services have any role?

Morrison: Yes, they did. They had a wonderful role. In fact, at that point in time [1983-86], social services at San Francisco General was a really strong department. The director was a woman who was absolutely wonderful. As in health care when the transition really began a few years ago, one of the first things that started going was social services. Any time that things get tight, you'll see social services being one of the first things to go. Which I think is ridiculous.

> If there are any two disciplines that really complement each other, they're nursing and social work. Most nurses, if they hadn't gone into nursing, would have probably been wonderful social workers. And most social workers, if they hadn't gone into social work, would have made very good nurses. The interesting thing is that we complement each other, but we have different skills.

> From the beginning, we needed the clinical nurse specialist--at that time which was me--to coordinate care management. I said, "Well, I think the ideal way to approach this"--this really wasn't in the literature--"is that we really need the team to be a master's-prepared social worker and a master's-prepared clinical nurse specialist, because the two will complement each other. And there's definitely enough work for both." Because the needs of the patients are so great.

> People were like, "Boy, this is really pie-in-the-sky. Where do you come up with all this stuff?" I got the opportunity to actually implement that before I left San Francisco General, and it worked. And I think anybody who's ever seen it would say that it worked. There's a lot of competition between nursing and social work. I didn't find that I always had administrative people behind me who supported it. After Maryanne McGuire moved downtown to the Department of Public Health, the person that followed her did not agree with my philosophy at all.

> Just before I left San Francisco General, I was in one of the most ridiculous situations, which is the kind of thing that you deal with a lot as an administrator, where I needed combined office space for the clinical nurse specialist and the social worker together. Nursing administration was willing to provide a very fine office for the clinical nurse specialist, but the director of nursing said, "I don't care about the social worker. We can just put a little desk for her in the

bathroom." [laughter] I wanted them to share an office together because they were working on the same issues together. It was unheard of. I wasn't getting support for that, and it created friction. I think it endeared me to the social services department.

Last semester when I was teaching nursing, I really kept emphasizing to nursing students, "Your ally when you get out there is social work. There's a number of things that you'll need to do when you become a nurse, but when you get out there, you look around to see where the social workers are, and you start working with them."

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- Morrison: We've got this traditional hierarchical system with a white male physician at the top who basically is dictating everything. Social work has basically aligned itself more with medicine than nursing.
- Hughes: Why would that be?
- Morrison: I don't think anybody can really answer it. It's easy sometimes to think, Well, let's just blame the problems in health care on doctors. That would be real easy. But you can't, because nurses have contributed to them a lot.

Comments on the Nursing Profession

- Morrison: The nursing profession is the largest professional group in the United States, by far. The only group that comes anywhere near us in numbers is attorneys. [laughter] And yet, for us to be the largest professional group in the country, up until a few years ago, we weren't really that well organized. A lot of people would say we're not that well organized today. Most nurses don't belong to their professional organizations. Nurses tend to operate in a vacuum. The work is so hard, and it's so intense, that the average nurse is a bedside nurse who does his or her work and then goes home. They don't have time to read research articles or to go to professional meetings.
- Hughes: Could that also be related to the diploma school mentality of nursing as strictly care-giving?

Morrison: Yes. It was task-oriented.

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- Hughes: If you're task-oriented, you're not thinking about professional organization, let alone attending meetings.
- Morrison: Exactly. People would say, "Oh, this is an excellent nurse," and I'd always say, "What do you mean by that?" "Well, she does her tasks so well." I don't know how many times as a nursing supervisor and nursing administrator, I would walk into a patient's room, and the staff would be so focused on the task that they had no concept of the patient.

I remember once going into a patient's room--this was a very sick, elderly patient who was incontinent of stool and urine--and two nurses were changing the patient's bed. The problem was that nobody was paying any attention to the patient, and he wasn't breathing. I remember trying to talk to the nurses after that, but they kept focusing on, "We did what you told us to do. We changed the bed." [laughter] That's an extreme, and a very bad way to make a point, but it's the only thing I could think of.

More on Hospice

- Hughes: Cliff, did the epidemic have a role in acceptance of the hospice model in this country? I believe it's a model that started in Britain. Am I right?
- Morrison: Yes. In European countries, Britain, Scandinavian countries.
- Hughes: For economic reasons?
- Morrison: No, I think just humanistic. I think the old world looked at death differently than we did and we do in this country. I've heard it said many times that the era of JFK [John F. Kennedy] and LBJ [Lyndon B. Johnson] made such major contributions to social issues in this country that, because of Medicare, Americans don't need any more to take care of their parents. That's something that we have to learn again. Almost every other culture in the world does, and Americans are really looked at in a strange way, that we don't do a really good job of taking care of our elderly. We're one of the few cultures in which that's not a priority. Age and death and dying--these are things that we just don't want to deal with. Hospice was definitely here before the epidemic, and it was growing, but it was growing in spite of, not as a planned proactive part of health care.

One of the things that had always amazed me about hospice was the level of dedication of the people that worked in hospice. A lot of people would say, well, they were too touchy-feely; they were a little on the mushy side, very sentimental, and all they wanted to do is hold your hand and tell you to cry. This sounds like an exaggeration, but I think that's where most people were coming from in those days, and I think a lot of people still are.

But it certainly became obvious to me that hospice was on to something, and it got my attention primarily because of the quality of people I saw working in hospice care. Even before AIDS, I had begun to think, Maybe that's something I'd like to do. And every time I'd mention it, someone would say, "Eh, don't do that. Why would you waste your career and work in hospice care?"

We had a hospice team at San Francisco General at that time [1983-84] because we had such a big oncology department and so many terminally ill patients.

- Hughes: And that preceded the epidemic?
- Morrison: Yes. Oncology is where the need had grown up, but there wasn't a real emphasis on issues of death and dying and the grief associated with it. Dr. [Robert] Brody, who was very instrumental, and is still, at San Francisco General, is a true hospice physician. He and the hospice coordinator [Eileen Lemus] were two people that I worked with very closely, and I started inviting them to come to these meetings and share their expertise. Dr. Brody talked to the staff when we were doing the orientation on pain management. These were things that hospice had already been doing in Europe and even in this country, but people rarely talked about it. The rest of us didn't really know that there was no reason for these patients to be dying in pain and gasping for air. There were ways to handle all of this; we could make people comfortable.
- Hughes: So the past pattern had been to discharge patients without any plan for handling these problems?
- Morrison: I think it would be unfair to say without any. The systems in place were doing what they thought they could, but I think we were totally missing the boat. We were simply not meeting the needs of those patients. And AIDS, like it did with everything else, really pushed that issue right up front and put it in everybody's face. Also, because we were looking for quick fixes, quick solutions to everything, it was logical to start trying to sell hospice care. I used to say, and so did a lot of other people, "Hey, hospice can really help us a lot here."

One of the things I tried to make clear was hospice care wasn't for everybody. It was part of the educational process that when patients came in, you started talking to them about no codes, about how did they feel about hospice care. We needed to talk to patients as they came in about the issues of death and dying. We needed to know before they reached this point at the end, what did they want? What were their wishes?

We'd never really quite dealt with that before, not at that level, not at that intensity. So that's where hospice really came in, because they were the experts at doing that. They'd been doing it all along.

Hughes: And so did you leave some of that discussion to hospice?

Morrison: Yes.

Hughes: Hospice came in on 5B?

Morrison: Yes.

More on Shanti

Hughes: Wasn't Shanti dealing with similar issues?

Morrison: Yes, they were, and there was some crossover. Shanti had a little different approach, but yes, there was certainly a real kinship between the hospice people and the Shanti people. They understood each other.

> One of the first things that was a problem for me, and the way I dealt with it was I didn't deal with it, was the touchyfeely issue. That was the excuse in the beginning: "We don't want hospice to have a big role." But at least they're more traditional than Shanti.

> Shanti already had this reputation of, "Ugh, these people hug each other all the time; it's just ridiculous." Well, in health care, nobody ever touched anybody, and you never touched patients unless you were doing something to them. I recognized right away, these were patients that were longing to be touched, that needed to be touched. They felt isolated, not only because of their illness but because of their lifestyle. It was like everything was out, it was just there, and--.

Hughes: Did you change your personal style with patients?

Morrison: Oh, yes. I went to nursing school at a time when I was told, "You are male, and males have to be more careful than females. You <u>never</u> touch a patient unless you're doing something to the patient, <u>never</u>, ever." You would never hold a patient's hand; you would never hug a patient; you would never sit down on the bed--that was something that was an absolute no-no. A nurse never sat on a patient's bed, ever. It was considered to be bad nursing practice. And god forbid if you should hold a patient.

> Holding a patient sometimes means that you've got to actually get in bed, and lie down next to them, and cradle them, and hold them, because they're too sick to get out of bed. That's something that nobody had ever seen before, and it created lots of problems in the institution. A lot of people, physicians and nurses, were very uncomfortable with it. They'd come in, "[tsk], Well, they're up in bed, god knows, having sex or whatever." [laughter] This hadn't been done before.

Hughes: You were letting your professional and personal barriers down?

Morrison: Oh, yes.

- Hughes: The engine of all this was your perception of patients' needs, rather than worrying about rules and regulations?
- Morrison: Yes. I saw myself as a facilitator and a role model, so I acted it out. Even when I was uncomfortable doing it, I did it, because I thought it was so important for people to see me doing it.
- Hughes: But you must have had some limits.

Morrison: Oh, yes. [laughs]

- Hughes: I'm not thinking of sex; I'm thinking of the emotional trauma for you as a care provider.
- Morrison: Yes. Well, that was always one of the excuses: "You shouldn't do this, because this will burn your staff out immediately. They won't be able to handle this." So that's when I said, "Okay, we need to provide support mechanisms for staff."

Staff Psychological Support Services

A Non-hierarchical System

Morrison: This is one of the things that I've written quite a bit about as well: I think it's the responsibility of administration, and if it's nursing, nursing administration, to allocate the resources to provide support for staff. It's left up to the staff then to take advantage of it. Health care being the way that it is and with unions and everything, particularly in this city, nurses think, Well, administration should provide it, and make all the decisions about it, and we shouldn't have to participate in it if we don't want to. Well, that wasn't my take on it at all. I thought that it was important for administration to provide the resource, but the staff had to take on the responsibility of doing it.

> Some of them took to it like ducks to water and some of them didn't. If you talk to Diane [Jones] about it, I'm sure that she would tell you the discussions the staff was having at the time. I mean, a lot of the staff thought I was nuts. They liked me, they respected me, but I found out pretty quickly who didn't agree with me and who did, and for what reasons they came to work on the unit.

> I think as time went on, they all began to see a lot of what I was saying made sense, but in the beginning, they didn't. They were like, "This is really crazy stuff. You're really off your rocker. What are you advocating for us to do here? You're changing our role, and telling us that we have to accept responsibility for everything. We're used to a hierarchical system that has a head nurse that makes all the decisions for us. She's Mommy, she solves all the problems, and we fight with each other. We just go to the head nurse and she solves it for us. Somebody else makes our schedules and gives them to us. "

> I came in and said, "We're not going to have a head nurse. I'm a clinical nurse specialist. I'm the clinical coordinator here. You're all professional people, therefore, I have an expectation that we will all behave as professionals, and we'll problem solve together. If you have an issue with another nurse, then you try to discuss it with the other nurse. If the two of you can't work it out, then you can come to me, or we'll discuss it as a group in our regular meetings."

Again, it sounded great. People all said that they agreed to it, but in actuality, it didn't work out that way at all. They were pissed, and they were pissed at me. They'd come to me and they'd say, "You're not an effective leader, because you don't solve our problems." They wouldn't say it exactly that way, but that's what they meant. "We're used to this role; we want somebody to solve our problems."

What I said to them was, "This is a new day in health care. We're experimenting here. We've got to practice what we preach. We're criticizing the medical model; we're criticizing physicians. Well, we've got to own up to our own problems in nursing and our own deficiencies," and there were lots. "And if we're going to take our rightful place in health care and be decision-makers, then we have to take personal responsibility."

Developing a Self-care Plan

Morrison: So I took that a step further as I went on in my career. I would not hire a nurse today without that nurse developing their own self-care plan. And when I interviewed nurses, I'd tell them that. You want to see somebody flip out? Nurses will wig right out on you over that stuff. They don't like it at all. "What do you mean, develop a plan for myself? How am I going to take care of myself to do this work? That's the most nonsensical thing I've ever heard of." It's not; it's personal responsibility, because otherwise you will burn out.

Jim Dilley

Hughes: Well, what was available for staff?

Morrison: In the beginning, the Department of Psychiatry really didn't feel that they had a role in the whole AIDS thing, and when I went downstairs and started putting all this together, I purposely left them out, because I didn't really think that there was a role for them either. There are a lot of problems with psychiatry, far too many to get into here.

> But they didn't see themselves in that role. I knew that psychiatry is even more traditional than medicine and suffers from a lot of the internal issues of health care. Psychiatrists aren't necessarily that well-respected within

medicine. Psychiatry is still considered to be a real "soft" area.

Jim Dilley, who when I was working in psychiatry was doing his residency, began to come to Merle Sande's meetings. I had known Jim, and I'd worked with him. So the Department of Psychiatry finally decided, Well, maybe there is a role for us here in AIDS care. So they pushed Jim forward, which I was pleased with, because I thought he was the person to do it.

Then I was told, "You've got to create a role for him somewhere." So I thought, How can I come up with something to give Jim something to do? He could do some of the consults on patients that we thought were psychotic or suicidal, that Shanti couldn't handle the basic needs of. I thought, "Well, this makes sense: I'm implementing this support group for the staff, so hmm, it's logical. We'll just have Jim Dilley facilitate it, let him be in charge of that." Made sense to me. [laughs]

And oh, boy, what a big mistake that was. For about a year and a half, the staff fought with me and with him over it. This is where we first got into real issues about taking responsibility for yourself. Staff loved the idea of having a support system, and I'd asked them all. During their orientations, we'd talked about what people could do. I'd had other people come in, people from hospice, that talked about how they dealt with things.

It was obvious to me that you didn't just have to have a support group, that people did all sorts of things to keep in balance. People got regular body massage; some people did meditation; some people did gardening; some people did knitting. And we did find that knitting and crocheting and things like that were very therapeutic.

But the system was so focused on "Gotta have something hard," and here I was coming up with a lot of stuff that sounded too simplistic--gardening? Taking an exercise class? At the same time, I was talking about, "Hey, the basic infection control measure is wash your hands." The reaction was: "Don't you really kind of go to the simple side of things?" [laughter]

I found out within a very short period of time that the support group was a disaster. First of all, there had been no precedent for nurses, except in oncology to some extent, or health care professionals, whether it was nurses or doctors, to sit down with our peers and talk about what's inside of us: how much it hurts to be taking care of this young person who's dying, or how I can relate to this because he looks like my little brother, or because I might be gay myself, or whatever. We were not used to sitting in front of each other and showing our weaknesses, and that was exactly how it was perceived. So things of substance were never discussed.

Also, Jim Dilley had a style, because his psychiatric education had been pretty much a Freudian model, and he was a passive facilitator. Which I was used to, and I actually thought was good--because it fit with what I thought was needed. I knew that he wasn't going to push his agenda on them, but the staff immediately started coming back to me and saying, "Well, you tell us to go to these meetings and to talk about our feelings. Well, we do, and Jim Dilley just sits there and says, `Mmm-hmm, mmm-hmm. Well, how do you feel about this?' He never targets anything; he never tells us anything. All he does is just sit there and nod his head."

And I'm like, "Well, that's what his role is. He's not going to solve your problems. He's there to facilitate you solving your own problems, or to talk about your own feelings." They didn't like it. They didn't like it at all.

I actually began to write some from the psychosocial standpoint. We began to see that throughout the whole system, not only with nursing staff but throughout, at every layer and every level, there did seem to be all this angst. People were fighting with each other and not getting along, and there were a lot of territorial issues.

It was only after I began doing some work with Elisabeth Kübler-Ross that I came to grips with the fact that the issues of death and dying and sexuality and all these other issues were just so painful and so difficult to deal with. There isn't a model, a precedent for us to grab onto, so that when put in that kind of a situation, we tend to revert to behaviors that are the most comfortable for us, and the things that we're the most familiar with: Anger. So rather than deal with your own feelings about sexuality, death and dying, or whatever, you take it out on your co-workers. You create or you take a little incident, and you blow it out of proportion.

So the staff were coming to me and they were complaining that Jim Dilley didn't meet their needs, and they wanted me to do something. I'll never forget talking to Jim about it. He did the same thing with me. Now, I had known Jim for years, and he was like, "Hmm. Hmm. Oh. Is that how they feel? Well, how do you feel about that?" I got mad at him. [laughter] I said, "Now I understand what staff is talking about." I thought about it some more, and then I truly understood. Jim was right, but so was the staff. What he essentially said to me, without saying it to me, was, "Butt out. We will work through this. If you try to get into this, you're only going to make it worse, and you're being manipulated by your staff. Let me handle it." I took that cue; I backed off. Well, I just continued to get a lot of flak from the staff.

Appointing a Successor

Morrison: Then I went through a period [1986] where a lot of other things were going on. The hospital administration was in turmoil; I got promoted to director of medical nursing [1984-1986] but still maintained my title as AIDS coordinator. Because then I had a lot more responsibility hospital-wide, I knew I had to think about somebody to replace me. Of course, my idea was, Bring on another clinical nurse specialist. But because we had to make a decision very quickly and because everything was in turmoil, the person [Judith Spinella] that was coming on as director of nursing said, "From within that 5B staff, choose a head nurse." I'm like, "I don't really want a head nurse."

> Well, this director of nursing was a more traditional person. I found out later she didn't necessarily agree with where I was coming from in a lot of ways. She said, "Well, we don't have time to go through all this other stuff. Staff is complaining anyway, and there are all these issues and problems in the hospital; we don't have time to deal with appointing a nurse coordinator."

> So I appointed Alison Moed. And that worked very well, because Alison immediately began to function as a head nurse, and things quieted down almost immediately. They had a "mommy" to solve their problems.

> Alison and I were very close. We became even closer, and we're still very close today. After I left San Francisco General [1986], it was a couple of years later, I was having dinner one night with her and Linda Maxey, and Alison said, "I've never had a chance to tell you, but all the stuff that you would talk about, all the things that you did during that time, I thought that you were a weak administrator. I really thought that you didn't know what you were doing, that all this stuff that you were involved in just didn't make any sense. Although you were constantly trying to keep us informed and up to date on it, I didn't really buy into it that much.

"It was only after you were gone that it all made sense to me, because you were doing too much. After you were gone, there was nobody for me to go to." So a lot of what we originally started out doing did become part of clinical practice, and is still there today. Some of it's not.

Hughes: Even with a head nurse structure?

Morrison: Yes.

Hughes: Because Alison incorporated some of what you had done?

- Morrison: Some, yes. Diane Jones certainly operates in the traditional head nurse role, but maybe even less so than Alison did, because Diane never really wanted to be an administrator; she never wanted to be a head nurse. I actually went to her first, because I thought she was the one with the leadership qualities, and she said no, she wasn't interested. She wasn't interested for years.
- Hughes: Because she wanted to do patient care?
- Morrison: She wanted to do patient care. And for those next couple of years, Alison was the ideal person. She had the personality for it. She also had some psych background, and she had an appreciation for hospice, so there was a really nice feel to it. She was also a heterosexual female, which I think was important. A couple of the male nurses-one in particular that really wanted to be the head nurse--were absolutely furious at me. But he would not have been the right person at that time. He was very rigid; he wanted to control everything. And the nursing staff and the medical staff would have never worked with him, whereas the medical staff love Alison. So it all worked out well.

More on Dilley

Morrison: Getting back to Jim Dilley: during that transition period, where I became director of medical nursing and had to step away a little bit--I'd been the clinical coordinator for a year at that point and all this stuff was in place. It was still kind of mushy, and a lot of it hadn't caught on yet, but it was there. So then for the next two years, I had a different role. I was still responsible for 5B, but I wasn't on that unit all the time. I had other responsibilities. It gave me an opportunity to look a little more broadly. That was the first time that I began to actually look out beyond 5B, and then 5A, and began to see, Oh, this application is going further. People are paying attention to this nursing model, and it does have a broader application. They still continued to fight about these support groups.

So Alison came to me one day and she was like, "You have <u>got</u> to do something, Cliff. The staff is almost in a state of revolt, and it goes right back to you, so I can't do anything about it. What do you propose?" I said, "Well, I guess I should give up trying to control staff support services." I met with the staff, and I said, "Alison and I both are tired of dealing with this. Okay, I do feel that it's the responsibility of administration to provide the resource, but not necessarily to be involved. So I'm going to give the responsibility to you. I'll provide it; you do whatever you want to with it. You're in charge of it. If you don't like Jim Dilley, you tell him." And that's how I left it.

The next meeting, they went and told Jim they didn't need him any more. He accepted it and stopped. They turned around and hired a lesbian minister, who was wonderful. She actually facilitated their support for two or three years after that. After fighting over this for a year and a half, I just gave it to them and they solved it. Not exactly the way I would have, but they solved it.

Importance of Staff Support Systems in Nursing

Morrison: Now when I'm asked to consult on how programs should be structured, I say that I think that it's crucial to have support systems, not only for nurses who work with AIDS patients, but nurses period. I think health care providers need to have a support system to assist in dealing with the multi-faceted issues in health care, but particularly to deal with personal and accumulated grief.

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Morrison: --support system be in place, but for individuals to decide what it is they want. Some people will do okay in groups; some people won't. Some people will want to have individual therapy. Now, that's where administration balks: "Oh, you're proposing that we have a responsibility to support these people, but at the same time, let them choose whatever they want? If they want to do a hobby, we're supposed to pay for it? If they want to join a gym, we're supposed to pay for that? If they want to have one-to-one therapy, we're supposed to pay for that?"

I think the way to handle that is within your employee assistance programs or whatever, you have therapists on a consulting basis, so that if a nurse says, "I really do need a mix. I would like to see a therapist one-on-one once a month or so, but then maybe I can deal with groups." Or, "I'd like to do some yoga."

This is a hard sell. An administrator might say outside of the room, "I agree with you, but we're not going to pay for this." And of course, today, with the cost of health care, nobody ever would.

Burnout

- Hughes: Despite these problems, there was very little staff burnout in the early years, am I not right?
- Morrison: That's right.
- Hughes: How do you explain that?
- Morrison: I think it's because people felt this personal commitment. It's true what Maryanne McGuire said from the first day, when she looked at who I had chosen: "You chose all the troublemakers in this system. These people are going to make your life miserable," and she was absolutely right. But they also had the strengths that I was looking for, and I knew that they would all rise to the occasion, and they did. Even the ones that I disagreed with later on.

Hughes: So why wasn't there burnout?

Morrison: A lot of it was, they were very much aware that they were pioneers. In their initial orientations, we talked about, "We don't know what this epidemic means." In 1983, when we put this program together, we knew it was a virus. We were in a rapid learning mode at that point, where almost daily we were getting more and more information. We had actually talked about, "What are we going to do if all of a sudden, we find all our staff has AIDS?" Nobody dealt with those issues.

So there was this closeness, this camaraderie. People knew that they were on a mission; we were pioneers. We were doing

something that was different. On the other side of it, too, was this satisfaction as a nurse. They were really good, and so were the Shanti counselors, about talking about how fulfilling the work was. It was draining, but it was fulfilling.

And they created a lot of social situations for themselves. The nursing staff and Shanti staff started partying together. Almost every month, there would be a big party at somebody's house. And that was great. That was another way of dealing with stress and grief.

After a couple of years, you began to see who was beginning to wear thin on it, and those people who weren't taking care of themselves were the first to leave--those people that had a lot of personal issues that they weren't dealing with, for whatever reason, that working with this patient population brought up.

Ward 5B (Continued)

Visitors

- Hughes: When did the stream of visitors begin in earnest, and what impact did it have?
- Morrison: Oh, I would say it started almost immediately. It really became an issue, I'd say, about six months or so after the unit was opened. In my meetings with nursing administration, it would come up: "How much time are you spending sending out information? How much time are you spending showing people what you and the staff are doing?" And there were more and more requests each day. People were calling. First it was local, and then it was national. People would want us to send them information.

Paul had an assistant on his staff, and she put together packets and sent them out. But it was all about treatment and medical stuff. So I tried to do that on the nursing side, and media relations helped me some with that, and so did Paul's assistant. I copied some stuff from her. Everybody else had staff, but I didn't have a secretary. So I was trying to do it on my own.

Hughes: Did that become overwhelming?

Morrison: It did. I got letters every day from all around the world. Some people said, "Oh, how wonderful this is, and we're so proud of you." I saved some of the nastier ones: "You're a dirty homosexual; you're going to Hell. This is god's curse, and you're going to die." We started informing the hospital security about some of them when they would get a little ridiculous.

Security

Morrison: Probably within six to nine months after the unit opened, there was an incident that occurred in New York City where somebody in the middle of the night walked into a hospital where an AIDS patient was very ill and set his bed on fire. This happened late 1983, maybe 1984. I remember reading about it and tingling immediately. I immediately went to hospital administration and I said, "I am really concerned. That's happened in New York, but San Francisco has its share of crazies. We're (5B) very high-profile." At that point in time, all the doors at San Francisco General were open twentyfour hours a day. You could enter anywhere you wanted to any time.

> I didn't get a lot of reception. People were like, "Eh, you're a little paranoid about this." We had a couple of situations of crazy people walking onto the unit. So I put it in writing. Of course, that's always the quickest way to get anybody's attention. Very diplomatically, I pointed out that I thought that we had a problem, and that it needed to be looked at.

> The solution was that hospital security would start paying close attention to 5B, and if they got a call from us, they would come up immediately without hesitation, and in their rounds, they would make a point, on a regular basis, of coming around. And that helped, it really did.

Hughes: But the doors weren't closed?

Morrison: The doors weren't closed, and that still concerned me a lot. The Shanti staff and the nursing staff talked about that a lot. We made sure that everybody was aware of it. By that time, we'd also implemented policies about visiting; we let the patients decide that, and there were no visiting hours designated. So we set up this system whereby the nursing staff and the Shanti staff were very vigilant. If you saw somebody suspicious walking around, you immediately went to them and found out what they were doing there, and pointed out to them that they should not be there. Particularly at night, nobody should have been walking onto this unit unless they had a reason to be there.

Hughes: And that kept the incidents down?

Morrison: Yes. 5B/5A, as far as I know, has never really had any major incidents. There have been some minor incidents throughout its history, and I'm sure that they still happen.

Moving to Ward 5A

- Hughes: Well, in March of '86, the AIDS unit expanded from twelve to twenty beds.
- Morrison: Yes, we moved to 5A.
- Hughes: 5B was closed down as an AIDS unit?
- Morrison: Yes. We moved over to 5A, and 5A was a full medical unit that at that time wasn't being used. It gave us a lot more space. We had more meeting space; we had twenty patient rooms instead of twelve.

Hughes: Were there politics involved with the move?

Morrison: There were, but that move was actually very smooth. I coordinated most of it, and that went almost without a hitch. We knew from the beginning that if this epidemic continued, we would need a larger unit, or we would have to rethink everything. So it became pretty obvious within a few months that we did need more space, but then everybody was like, "Well, but maybe we won't need it that long."

> Dr. Sande saw the need for it; he pushed it, and he wanted it. And so it happened. I certainly was saying to everybody, "Moving to a bigger unit is not going to solve the problem." In fact, I was worried that we were creating the wrong expectations, because we had created this unit and had told all the staff in the hospital, "Well, you're not going to have to care for these patients; they're going to wind up on 5B." Well, 5B wasn't big enough, and within a few months we saw that

there were twelve patients on the unit, but there were still twelve AIDS patients outside the unit.

And moving to a twenty-bed unit didn't relieve us of that problem. It alleviated some of the pressure, but it certainly didn't alleviate all of it. So there were some real issues with that, because staff in the other parts of the hospital were like, "Well, we only went along with this AIDS unit because we thought that all the patients would wind up going there, but we still have AIDS patients."

The Consult Team

- Morrison: Before, on 5B, but certainly as a part of moving to 5A, we created a consult team. It started off with the doctor that later became the first medical director of the unit--
- Hughes: Michael Clement?
- Morrison: Yes. Michael Clement, a clinical nurse specialist, and a social worker made up the team. They would on a daily basis go out and see all these other AIDS patients. So that if AIDS patients were admitted to any other unit in the hospital, they just called us, and we had the consult team go check it out and see what the issues were.

And then the consult team began to prioritize what patients would be coming into the unit, because by that time, very few patients were admitted directly to 5B or then 5A. They were usually admitted to another unit, and then the consult team evaluated them and decided what their acuity level was, and then prioritized who, as a bed would open up, was going to be the next person to move into [5B/A]. Occasionally, we would have some empty beds when there were admissions and they'd go right into them, but most often they went to another unit.

Relations with the AIDS Clinic

- Hughes: How often would a patient come from the AIDS Clinic directly to inpatient?
- Morrison: Very often. And the good thing about that was that when it happened, usually the patient would come over with a physician or with one of the nurses. J. B. [Molaghan] or Gayling [Gee]

would bring them over, so we did have that kind of contact with the clinic staff, and that helped a lot. I think I mentioned this before: we didn't really have a structure set up for us to really communicate and coordinate the clinic and 5B, and we worked that out on our own. Gayling certainly didn't have to cooperate with us, but she did.

Hughes: Did it make any difference that you were a nursing unit, and the clinic was a medical unit?

Morrison: Yes, the clinic was UC, and the staff were UC employees. Inpatient was the hospital and the Department of Public Health, and we were all employees of the Department of Public Health. Yes, there were territorial issues; there were divisions; there were undercurrents. It really wasn't any different from anything else at San Francisco General. It's all part of this divide-and-conquer thing that I think we've unconsciously created. You've got a public hospital with a leading university medical school that provides and coordinates the medical care there.

> San Francisco General had always been looked down upon, and AIDS changed its reputation. You can mention the "General" anywhere in the world now, people think of it as a good institution now, a great institution, even. Back in those days, they didn't. It was the county hospital; it was the dumping ground. Nobody wanted to go there. And there was this hierarchy, this pecking order. UC people kind of looked down on the staff at San Francisco General. Even within San Francisco General, there was this pecking order: "I'm a UC employee; I'm not a DPH employee."

I was very much aware of that but never really appreciated it until I went back there a couple of years ago as a UC employee, and really felt it then and saw it from a different perspective. I heard from other UC people, twelve, thirteen years later, that if you're UC, you're better; you're more elite.

- Hughes: Because of these different affiliations, did it make coordination more difficult between the clinic and the inpatient unit?
- Morrison: Yes, it did, and I think it would have been next to impossible if it hadn't been that the issues were just simply so great that we had to do something. Gayling and I would work them out ourselves, in spite of other people. There was a respect between the nursing staff on the inpatient unit and the outpatient area. Both oftentimes would think that the other had an easier job. I think the nurses in the clinic probably

thought that the nurses on 5A had it made, and certainly I heard a lot: "God, they've [the nurses in the AIDS Clinic] have really got it made over there." But they didn't. We were all in the same boat.

But yes, we did a lot of problem-solving, and a lot of times in spite of the system rather than the system assisting us. [tape interruption]

Morrison: The success of everything that happened at SFGH was truly a partnership. I don't think we started off understanding exactly what all that meant, but certainly within a year or so, it became really clear. I think the nursing staff felt very satisfied. They were truly the heroes; they were the ones who were responsible. Sure, I might have had a lot of the ideas, but I couldn't carry them out. They had to do it, and they did.

Money and Prestige

- Morrison: I think that inpatient services had Dr. Sande's support, Dr. Sande's praise. I think he recognized almost immediately that this unit made his life easier. It made it easier for his interns and residents and medical students, and he didn't hear the complaints. It just made sense. Plus the fact that we all got praise for what we were doing, and we got attention and publicity for it.
- Hughes: And you were bringing a lot of money into the hospital.
- Morrison: Money, not exactly. Everybody recognized that the system was benefitting tremendously from this. A number of people started coming on board the AIDS epidemic because they saw that it was going to be a gravy train for a while. And that wasn't just at San Francisco General; that happened nationally.
- Hughes: When would you say that trend began?
- Morrison: Almost immediately. As soon as positive press started and it became obvious that there was money available.
- Hughes: About the time that 5B was formed?
- Morrison: Within a few months afterwards.

- Hughes: Did it become obvious around that time that this epidemic was not a fleeting phenomenon. That for the foreseeable future it was here to stay?
- Morrison: Yes. And I think that's when it actually began to drive the system. There's still a reluctance to acknowledge it, but I think the HIV epidemic has pretty much been steering health care for some time now.

Now, one of the earlier criticisms was that, Well, if this is going to be what all of you are saying it's going to be, AIDS is going to be responsible for the collapse of the health care delivery system in the United States. I used to always say, "No, AIDS is not going to be responsible for the collapse of the health care delivery system. It was headed in that direction on its own. Actually, AIDS might be its salvation, because it will force us to deal with the issues before we actually reach that point of collapse."

A lot of it had to do with the fact that we went through two Republican administrations in twelve years. I was certainly very optimistic recently when I thought that under the Clinton administration we were going to have health care reform. We will have health care reform, but now we're going to back into it through the back door. It's going to happen in spite of, not because of.

Centers for Disease Control and Prevention

Role

- Hughes: How important was the CDC definition of AIDS to what you were doing, and did you follow it fairly strictly, or did you have your own working definition of what an AIDS case was?
- Morrison: Dr. Sande's meeting was a real benefit to me, because there was a lot of discussion about that, and then Dr. Curran would come out and we'd discuss it. Yes, I pretty much supported where CDC was coming from. Actually, I've always been very supportive of CDC--the assistance that they provided. From what I gather, it's not as great now as it was a few years ago. But CDC did provide some leadership. Later on, I think that they have certainly manipulated things to an extent, and they've certainly tried to control some things.

People like James Curran, and other people as well, were well meaning. They were committed. They were able to do a lot of things in spite of the federal system that they were operating in.

- Hughes: CDC is largely an epidemiological organization, and epidemiology had more of a role in the very early days of the epidemic. So was it natural that CDC would drop out to a degree as time went on?
- Morrison: I don't think they would have, except for the fact that as the epidemic grew, it also became more controversial. Then it became a big political liability, because the leadership at CDC is pretty much appointed by whoever is in power. I think that there was the attitude: "Oh, let's back off on some of this stuff [epidemiology]." The NIH began to play a bigger role, so it was logical that CDC's role would lessen. I do think that politics pushed a lot of it. It would have happened anyway, as HIV/AIDS became more of a political issue as time went on.

Definition of AIDS

- Hughes: Did you find that most of your cases could be embraced by the CDC definition of AIDS?
- Morrison: Yes, most of them. The staff always joked about how the system has to have its rigid definition for everything. So we operated in spite of it, but not in a disrespectful way. It was something we could live with. We recognized right away and would discuss different cases in case meetings: "This case doesn't exactly fit these criteria." And oftentimes, Jim Curran or somebody from CDC would listen to us, and then things [the AIDS definition] got changed as a result of it.

AIDS Nursing on the East Coast

Morrison: We went through a real period of exchanging a lot of knowledge and experience nationally. I was always proud of the fact that we didn't turn people away when they came to get information, and we shared a lot of our information with our nursing colleagues and medical colleagues on the East Coast. I don't think a lot of nurses on the East Coast appreciated what we did in San Francisco. I had a number of nurses say to me, "Well, you can do this here because it's San Francisco and it's San Francisco General, and the gay community has political clout. But this won't happen anywhere else."

- Hughes: You said in an earlier session that the nursing profession on the East Coast did not take an active stance in AIDS care. Why was that?
- Morrison: We in San Francisco were criticized from day one, "Why do you want to do things differently? AIDS should be handled the way that everything else has always been handled." And my response always was, "Well, we never handled anything else very well, so we've got to change at some point." There wasn't a lot happening in the Midwest. Everybody thought that there would never be any cases in those rural areas. In nursing and health care generally, it was the status quo: "We're not into change. We're content to leave things as they are."

Also there was this fear--AIDS was a gay disease. That's how it was referred to. And it's still thought of pretty much that way, and it's got all of these stigmas around it.

- Hughes: Well, and if it's not a gay disease, it's IV drug users, who are also stigmatized.
- Morrison: Yes, exactly. Everything around it was stigmatized. Michael Stanley, my assistant, and I were joking the other day about the new heterosexual strain. We're wondering how long it will be before people stand up and say, "I have heterosexual AIDS." [laughter] There's always been this emphasis on, "How did you get it?"
- Hughes: I take your point, but on the other hand, AIDS was seen as a gay disease on the West Coast, too. So what was there about West Coast or San Francisco nursing?
- Morrison: Well, San Francisco I think even more than West Coast, because L.A. didn't do what we did. They did it differently; they did it their own way. I think later on, they copied some of the stuff--"copied" is an unfair word. They duplicated some of it. I'd always said, "Hey, I'm not saying that what we did as nurses was exactly the right way to go." I shared all the information I could with anybody who wanted it, and said to them, "Do what I did when I put all this together: go through it and take what you think will work for you. I'm not throwing out a blueprint here that says you've got to design your programs exactly the way this one is, or it won't be right. I think you can adapt it." And I think that's what happened.

There's always been--and I didn't realize exactly how much --a competition, certainly in nursing, and throughout health

care really, that is multi-tiered. It's at the academic level, it's at the political level, and it's at the practice level, in both medicine and nursing. Through all of our bureaucracies, there's envy and there's jealousy.

California, particularly San Francisco, had been acknowledged for a long time as a very liberal area that spent a lot of money on health care. And because we were kooky, we were always trying all these things, all this touchy-feely stuff. East Coast people were very quick to say, "We'll never do any of that, because it's too touchy-feely." Well, it's the same thing I heard here.

If you go to New York now, you see that people touch each other. In fact, probably the single most visible change that happened--and I think it's a direct result of this epidemic--is that health care providers show an emotional side of themselves that they never did before. We touch each other, and we touch our patients, and we touch our patients' families, and we hug people. Something we never did before.

San Francisco Model of AIDS Care

Description

- Hughes: Cliff, we've been talking about this indirectly all along, of course, but for the record, would you define the San Francisco model of AIDS care? [laughter]
- Morrison: Oh, that's wonderful. I haven't been asked that in years. I'll try to remember what I used to say when people would ask, "Define the model." I would always start off by saying, "Well, I'll be criticized for saying this, but it's not actually a model. It's this eclectic gathering of different things that came together, and you could call it a model if you want, but it certainly was never set out that way."

The San Francisco model was an attempt to coordinate resources, to coordinate services, with an emphasis on institutional care, but for the first time with recognition that community-based care played a major role, and that every aspect depended on every other aspect, and that none of us were operating in isolation, that we were all very much dependent on each other. I used to say what makes it stand out is the three "C"'s: coordination, communication--what was the third "C"? [Cooperation.]

- Hughes: Comprehensiveness?
- Morrison: That probably was it. There was a lot of talk about comprehensiveness and coordination. Obviously, you can't always achieve that.
- Hughes: Do you think that it turned out to be a comprehensive and coordinated model?
- Morrison: Probably the most that I'd ever seen, and maybe the most that had occurred up until that time. Yes, it was. I was amazed. I had never seen health care delivery reach that point.

Now, I think what's really controversial, and I've certainly been saying it for a long time, it was short-lived. Because we were operating not knowing what the future was going to hold, what we set up made so much sense but within a very short period of time became obsolete. But we rode on the bandwagon with it for a long, long time, and I think we've just begun to begin to let it go. The rest of the world now realizes that the San Francisco model hardly exists the way that it was originally intended to, for a number of reasons.

Compromises

Morrison: The first thing was, I think we ourselves corrupted the model. I certainly did. We compromised too much. I started off, and I think Paul and a lot of other people started off, thinking, Okay, if we're going to do this thing, then this is the way to do it. Like my approach with case management: I was a purist. You either do it the way it's supposed to be done, or you don't call it case management, or you don't do it at all. But we all compromised very early on.

> Merv Silverman and I talked about this a lot. Where some of these major compromises occurred was at his level, at the meetings with the AIDS coordinating committee downtown at the health department. I constantly compromised on things to gain acceptance or to get people to cooperate with us.

Hughes: Give me an example.

Morrison: Well, case management was actually the first major compromise. First of all, everybody was using the term and nobody knew what it meant. I like to think that I did, and I would talk a lot about what were the components of case management, what were the objectives, what were the goals. Everybody would just sit and listen. Even Merv said to me one day, "You're the only person that I've ever met who really seems to have a real concept of what case management is. I've learned a lot listening to you talk about it so much." It was like beating a horse.

> Looking back on it, I'm not critical, because I think it had to happen; we had to get support in the community. We immediately began to compromise. Well, I believe in compromise; I think that's the democratic way. That's why the government is in the mess that it's in today: we're not compromising enough. Most people don't like compromise like they don't like change, but it's better to compromise and get some of what you want than to lose the whole thing.

Hughes: How did you compromise in respect to case management?

Morrison: The coordination piece. There was a lot of discussion downtown about how everything would be coordinated. Dr. Silverman was dealing with a lot of the politics of the community, and by that time, he had become too much of a central figure--by his own admission. San Francisco is actually small and provincial in many ways. People here don't want to hear that, but it is the truth. This is, what, the fourth largest metropolitan area in the country, and yet the director of health was accessible. You could walk right into his office if you wanted to. Actually, if the [ex-]mayor [George Moscone] hadn't been assassinated, you probably could still do that with the mayor.

> So it makes it a little bit different here, and I think Merv found himself in a situation of being too much in the media. Many good things came about as a result of it, but also other things, the bad part of it, that a lot of us all of a sudden were playing to the media. We began to think of ourselves as being more important than we really were. I always tried to take myself back to, I'm not that important; we're all part of a team here. This is too big for any of us to handle, and we can never, ever lose the idea that there are patients out there. This is patient-centered care, and we're doing this for <u>their</u> benefit, not ours. But I kept thinking, Well, I can use this epidemic and these issues to make the changes that need to be made in nursing and health care.

The compromise which was a major mistake, but had to be made, was the coordination piece. There were a number of

people in the group that understood what case management should be about, but we understood the politics of this community, and the first big breach was in these different community organizations. We were talking about who was going to get money and what their role was going to be. There was a group of us that was saying early on, "Let's don't duplicate services. There's a role for everybody, but let's don't have them duplicating each other. Shanti is very good at emotional support and volunteerism. Let's let them do that. San Francisco AIDS Foundation: give them AIDS prevention and education."

By that time, ethnic groups in the city were saying that they needed a piece of the pie. Everybody wanted to have their own isolated piece and be totally responsible for theirs and not have to coordinate with everybody else. The decision was made to let them do that. The argument was, "Well, but it's working so well. We all communicate with each other." And it did. I would even listen to my own arguments and say, "That didn't make any sense. Anything I need, all I have to do is pick up the phone. I know who to call." Without thinking, What's this going to be like a year down the road? That there's going to be ten times more of us, that there's going to be lots more patients, that this is going to be an enormous bureaucracy and we're never going to be able to communicate with each other.

Duplication of Services

- Morrison: And that's exactly what happened. Within a year, although we were riding the crest of this great model, the model itself was out of control, because we did wind up duplicating services. Every agency was trying to recreate Shanti. And there was all this duplication and waste and people creating their own territories.
- Hughes: And lack of communication.
- Morrison: Yes. What baffled a lot of people that were working in AIDS from almost the beginning was that, by this time, there were all these other people coming into it, and they were there for different reasons. They were there because there were jobs and there was money, or careers to be made or whatever, and there was resentment.

The interesting thing is that the way we dealt with it was that we didn't deal with it. I don't think it's anybody's

fault. I remember talking to Randy Shilts about this, and he said, "Oh, it's Merv Silverman's fault." I said, "No, it's not. It's real easy to blame him. He is director of health." Nobody knew. [laughs] We were playing in the dark; we were doing things that had never been done before, and, hopefully, we were learning from our mistakes.

We learned very quickly that we were making really big mistakes in this city with what we were doing about coordination, and particularly in this loose thing that we were loving to call case management.

Silverman's AIDS Medical Advisory Committee

- Hughes: Now, Cliff, it makes me think of another of your activities, which was a membership on--I guess it's Silverman's medical AIDS advisory committee?
- Morrison: AIDS advisory committee, yes.
- Hughes: Could Dr. Silverman's AIDS advisory committee have served as a coordinating body?
- Morrison: Yes.

Hughes: Was that Silverman's intention in setting it up?

Morrison: Yes, I think so. I think it's part of the three C's. He saw it also as the coordination and communication component. There were maybe twenty-five of us, and we'd all go down there to meet at the health department. It was great. He would have some snacks there for us, and we'd sit there and discuss the issues. "Okay, I'm going to do this, and Cliff, you'll call over there and you'll do this," and we could do that. It made so much sense, and it had never happened before, and we all pretty much agreed. There were arguments, and the usual stuff, but there was a lot of agreement as well, so it made sense. It [the model] was so logical, and Merv was very proud of it, and I think he had a right to be.

> We were still dealing with a lot of fundamentals about bringing in community groups, because over half of the people on Merv's committee--in fact, most of them, I think--were from community groups. He understood, as did the mayor, the importance of trying to have as much input as possible and working with these different community groups, because the media was always looking for somebody who disagreed. We went

through this period where it was like everywhere you turned, there was some reporter or journalist with a microphone and a camera shoved in your face, so the temptation was just too great. So everybody had something to say.

Hughes: You said that overall coordination did not occur.

- Morrison: It did for a short while, not so much because of the systems we put in place, but because of the individuals that were doing it. And then it began to crack almost immediately as the national and the state money came in. The bureaucracy just mushroomed almost immediately. Then we really began to see that, We're not cooperating, we're not coordinating, we're not communicating. That's what the three C's were, by the way: cooperation, communication, coordination.
- Hughes: You took steps to coordinate?
- Morrison: Yes, we made some quick-fix gestures. I think Merv certainly provided a lot of leadership in that area. He's such a genteel, committed person, and there's a warmth and genuineness about him that people relate to, because he's basically charismatic. But because I saw that, and I've always adored the man, it never dawned on me that there were people out there that didn't like him, that thought his motives were totally different. I remember the first time I heard somebody say, "Well, maybe he doesn't have our best interest at heart," and I was like, What? I've never met anybody in public health that was coming from where he was coming from. He was open to everything.

There were people that thought that he wasn't providing leadership, that he was playing to all these different diverse groups and that he was trying to run things by consensus, and to some degree he was. Where the bathhouse issue got totally out of whack was that Merv was trying to get consensus because it was something we did need consensus on. The committee all agreed to a consensus approach. Then when the media was in front of them and they were standing downtown at a press conference, nobody would support it, and Merv was left standing up there by himself to deal with the issue of closing the bathhouses.

AIDS Hospital Services Elsewhere in San Francisco

Hughes: [tape interruption] What role, if any, did you have in efforts to encourage other hospitals in San Francisco to take

responsibility for AIDS patients? My question is prompted by the realization that in '83-'84 people at San Francisco General became concerned that the hospital was going to become an AIDS hospital, to have that image. Which, of course, did happen, but in a very positive way. What AIDS services were instituted at other hospitals?

Morrison: At that point, there was actually very little going on in the other hospitals. Other hospitals around the country began to look at what we were doing at San Francisco General and to develop some sort of program, some sort of approach, before other hospitals in this area did, for the very reason that you mentioned: because the other hospitals felt like, We don't want to deal with this disease. We could never do what San Francisco General has done. First of all, the idea of private hospitals working with communities was not something they wanted to do.

> The majority of patients that were coming in by '84-'85 were still private patients. It's one of the things which really made 5B and then 5A pay for themselves. Nobody wanted to admit it, but these were the only patients at San Francisco General that paid their hospital bills. They had private insurance, by and large.

In the private hospitals, AIDS patients were being taken care of quietly, and the numbers weren't that great at that point, and things didn't really change so much in these other hospitals until those numbers did become significant. And then they had staff and patients that started demanding, "Well, they're doing this over at San Francisco General; why don't you do it?" But early on in the epidemic, we heard things like, "Oh, well, I go to a private hospital. I wouldn't go to San Francisco General."

But it is very interesting that it was hospitals in other parts of the country that began to, in some way, try to adapt what we were doing to fit their needs before other hospitals in this area did.

Hughes: Some of that perhaps was because you were here, providing the service.

Morrison: We were here, and because of the gay focus. Nobody else wanted to admit that. In New York, the gay community was bigger than here and had already demonstrated political clout. But San Francisco was the only city, and probably still is to a great extent, where one can be openly gay and not feel the discrimination that you would feel on the East Coast. I still have a lot of colleagues in New York that are not "out" at work. I can't imagine living that way. But people do.

AIDS Train the Trainer Program, California Nurses Association

Morrison: A number of us spent so much time showing people around, and it became a conflict because how much of my time could I do that? We had people coming from all over the world. Paul's assistant would coordinate these tours, and they'd come through. They always wanted to talk to us, and staff nurses didn't have time to stop. I didn't either really, but I did.

> Before I left San Francisco General that I began to see that we needed to work with professional organizations. Helen Miramontes was president of California Nurses Association at the time, thank god--

Hughes: Why do you say that?

Morrison: Well, because she literally pushed through on her own the AIDS Train the Trainer program. CNA wasn't that anxious for it. We wrote the grant proposal for it, and it got funded. We didn't think it would, because we submitted a proposal along with California Medical Association and California Hospital Association, and Merv actually coordinated the California Medical Association's one. So I made an assumption--I'd never written a grant application before--we weren't going to get it. I did it because I thought it was important for us to do it, and I wanted the experience of doing it. I never thought we'd get it, and we did.

> Later on, the person at the state level that was assigned to be my project officer was very good. She was very strict and certainly wanted to make sure that everything was done right down to the letter of the grant. One day I asked her, "Why did you give us this grant? We were competing with the big boys." She said, "Yours was the only one that made sense." [laughter]

> The way we approached it--I think a lot of it came from my education background--you have to make an assumption that not everybody thinks at your level. If you're going to put concepts across, you do it in the most basic way, and you don't make it complicated. I think that's what worked for us in that case.

I began to work through professional organizations, first with California Nurses Association, then later when I became a member [1988] of the American Academy of Nursing, through the Academy of Nursing, then the American Nurses Association, then with other state organizations, and then through the federal government. I began to lecture and consult, and that was the way that we got that information out. And then all of us, myself included, were invited to a lot to hospitals to look at what they were doing and to make suggestions and recommendations about how they could change things. So that's how that model spread.

The Epidemic's Personal Impact

- Hughes: Well, Cliff, there's of course much more that we could say, but I think we have to wrap this up. I'll ask you one final question: you've been associated with the epidemic for fourteen years.
- Morrison: Yes, fourteen.
- Hughes: What impact has it had on you as a person?
- Morrison: Oh, boy, that's a hard one. It may be years before I actually know what that is. It completely changed my life in a number of ways. The impact? A lot of wear and tear. I think it forced me to grow up a lot quicker. I think that I was a mature person [at the onset of the epidemic], but there was still a very immature side of me. I was only thirty years old, and being a gay man, I wanted to see myself as youthful. I liked playing naive sometimes.

I think AIDS changed all that for me. I saw what was happening around me with my friends and my colleagues, and I saw how people responded, and I saw how my own family responded. They either denied it completely; they didn't want to hear about it, or they made an assumption that I had it. That's been the humorous twist to it throughout these years. It surfaces everytwo or three years, that I must have HIV. From the beginning, everybody assumed that I did. Even I probably thought I did.

Hughes: Because, why else would you be associated with this disease?

Morrison: Well, yes, and I certainly knew that I'd been sexually active, so--. Maybe not to the extent that a lot of the patients that I was seeing were, but I knew that I'd been exposed to it. We didn't have a test for it then, so when the test did come along and I tested negative, I was, Wow--I can't believe that.

Hughes: Why did your family make that assumption?

Morrison: Well, I certainly don't want to put too much blame on my biological family--I essentially have two families. My biological family on both sides are really not very educated, and do not have a real awareness of alternative lifestyles or differences. And I was always an enigma to them, anyway.

> My family has never really come to grips with my sexuality, which means that I probably haven't either. I don't know how much one can. It's all been so complicated and so interwoven. I sometimes try to tease it all out and I can't, so I stopped doing it. What is most important to me? The epidemic, or its significance to the gay community, that we were the first that were affected by it?

> Some of my most challenging and rewarding and fulfilling experiences personally and professionally have been over the last fourteen years. During the same time, I have experienced the lowest points in my life--depression, guilt, fear, panic, the unknowing how far is this going to go, what's it going to do to me, why am I still doing this? And then what I'm struggling with now: am I no longer useful in the epidemic? On the one hand, it would certainly seem that way. I can't seem to be able to get a job in AIDS any more. How much of it is me? How much of it is the way things are going? How much of it is perhaps I'm intimidating or perceived to be too pushy or too gay or too whatever.

> We're still dealing with a lot of the basic issues that we were dealing with fourteen years ago. They're not resolved-the basic issues of death and dying and sexuality and all of these dark things that we never talked about and recognized.

> When I was younger, I wound up doing a lot of those things because I think I was perceived as being, Yeah, okay, he's dedicated. He might be a little on the smart side, but he's a young little hot-head. Well, now I'm older, middle aged, and my hair is gray and I've got lines in my face, and I weigh a lot more than I used to, so I'm different. There's a more serious side to me now than there was before. I think to a great extent, it's not so much me, it's what I represent. But I'm not real sure about that. I still have a lot of work to do on it.

> I've done a lot of therapy. I'm just coming out of a very deep clinical depression that I was in for several months

because of personal loss. And yes, it's been profound. I'm not really sure exactly what all of the changes were about, and maybe I'll never know.

All I can say is that I wouldn't have traded who I was at this point in my life and my career for anything else. I'm so glad that I was where I was when I was, and that I was a nurse.

Hughes: Thank you, Cliff.

Transcribed by Shannon Page Final Typed by Julia Rechter

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DIANE JONES 2768-22nd Street SAN FRANCISCO, CA 94110 (415) 641-7832

EMPLOYMENT HISTORY

SAN FRANCISCO GENERAL HOSPITAL (1982-present)

* Head Nurse - AIDS Special Care Unit (1990-present); manager of a 20-bed in-patient unit caring for all stages of HIV disease; responsible for overall delivery of care, quality assurance, education and training of staff; supervision of a staff of 32; liaison and coordination with a multi-disciplinary team involving physicians, social workers, counselors, nutritionists and pharmacists.

* Staff Nurse - Pediatrics (1989-1990); staff nurse on a 16 bed inpatient pediatrics unit caring for children from newborns to 17 year olds. Specialty in trauma, child abuse, and sexually-transmitted diseases.

* Staff Nurse - AIDS Special Care Unit (1983-1989); founding staff member for this nationally-recognized in-patient unit caring for people at all stages of HIV disease; served as charge nurse and clinical preceptor.

* Staff Nurse - General Medicine (1982-1983); nurse on a 34-bed acute care medicine unit; specializing in management of alcohol and drug related conditions, peritoneal dialysis, oncology, HIV disease. Served as charge nurse on the night shift.

SAN FRANCISCO WOMEN'S CENTERS (1975-1982): Community organizer; core staff of this community-cultural center organizing around women's issues; coordinated sponsored projects, providing technical assistance to new and emerging organizations. Specialized in administration, organizational development, programming and financial mangement.

PEACE CORPS (1972-1974); Heath Educator, Togo, West Africa; developed a comprehensive health education program in local elementary schools in Northern rural Togo; set up prenatal and well-baby clinics and worked with lay midwives to develop health education curriculum; organized public health construction projects including wells, latrines, cisterns, maternities.

EDUCATION

Baccalaureat - Dames de Marie, Bruxelles, Belgium 1969 American College in Paris - 1970 TUFTS University - Bachelor of Arts (History and Political Science) 1972 City College of San Francisco - Registered Nurse 1982

LANGUAGES English and French



Curriculum Vitae

Clifford L. (Cliff) Morrison, MS, MN, RN, FAAN 655 Corbett Avenue, #406 San Francisco, California 94114

 Residence
 415/824-1969

 Business
 415/208-4354 and 206-1644

 Fax
 415/206-0796

Background Summary

Over 22 years experience in Healthcare Service, Administration, and Public Health with particular emphasis on planning, development and implementation of programs for direct service in the community and in the institutional setting. Additional expertise in case management, healthcare policy, grants development, professional and community education. Over 11 years experience in HIV issues.

Education

- 1979 M. S., Education and M.S., Community and Mental Health Nursing, University of Miami, Coral Gables, Florida.
- 1976 M. S., Health Care Administration, specialization in Health Planning, Florida. International University, Tamiami Campus, Miami, Florida.
- 1974 B. S. in Nursing Education, Florida International University, Tamiami Campus, Miami, Florida.
- 1971 A. S. in Nursing, Florida Community College at Jacksonville, Florida.

Certification and Additional Education

- 1977 Emergency Medical Services (E.M.S.) Administration, Certification, Florida International University, Tamiami Campus, Miami, Florida.
- 1983 Shanti Counseling Program for Persons with Life Threatening Illnesses, The Shanti Project, San Francisco, California.
- 1984 American Nurses Association Certification for Clinical Specialist in Psychiatric Mental Health Nursing. January, 1984 to 1991.
- 1986 Life, Death and Transition, workshop with Elisabeth Kubler-Ross, M.D., Hawaii, February, 1986. Follow-up intensive training, Syria, Virginia. May, 1986.
- 1986 Management Development Systems for Organizational Effectiveness. Robert Hicks, Ph.D., San Francisco, California.
- 1986 American Nurses Association certification for Nursing Administration. June, 1986 to present.

1988 Fellow: The American Academy of Nursing.

Registered Nurse License, State of California #RN311978, through September, 1995. State of Florida #57477-2, through March, 1995.

Professional Experience

- 1/94 Director, Clinical Services, Epidemiology Prevention Intervention (EPI)Center, San Francisco General Hospital, University of California, San Francisco, CA.
- to Responsible for 5 components of epidemiology service, including HIV Counseling and Testing, Occupational Exposure Program, Hospital Infection Control, and
- Pres. Public Education.

12/92 Coordinatior, Continuing Education, Center for Occupational and
 to Environmental Health, School of Public Health, University of California,
 12/93 Berkeley, CA.

- 1991 Consultant, providing independent consulting services to numerous health care to organizations and institutions in areas of program planning and development,
- Pres. organizational development, case management, communication, education, conference planning and coordination, counseling and HIV care and services.
- 1/87 Deputy Director, The Robert Wood Johnson Foundation AIDS Health
- to Services Program, at the Institute for Health Policy Studies, School of
- 4/92 Medicine, University of California, San Francisco. Administratively responsible for monitoring nine project sites nationally in 11 cities with a budget of \$17.2 million. These demonstration projects were established to set up coordinated patient care services utilizing the model developed in San Francisco. Also responsible for providing technical assistance, clinical consultation and budget monitoring to the projects as well as maintaining communication with projects and the National Advisory Committee. Developed a national program management information system (MIS) and a model for case management, as well as analysis of data and participation in policy development and analysis. Supervisors: Mervyn F. Silverman, M.D., M.P.H., Director, AIDS Health Services Program, and Philip R. Lee, M.D., Director, Institute for Health Policy Studies.
- 1987 Assistant Clinical Professor, University of California, San Francisco,
- 1992 Institute for Health Policy Studies, School of Medicine.
- 1982 Assistant Clinical Professor, University of California, San Francisco, School 1992 of Nursing, Department of Mental Health, Community and Administrative Nursing.
- 1986 Director, California Nurses Association, AIDS Education and Training
- 1987 Program. Authored a proposal and obtained a grant for \$250,000 from the California Department of Health Services. Planned and established statewide education and training program for 19,000 health care providers.

1986 Consultant to the San Francisco Department of Public Health, responsible
 1987 for a \$400,000 grant from the California Department of Health Services
 to support and monitor contract providers and document the need for an
 intermediate care facility for persons with HIV/AIDS in San Francisco.

- 1984 Director, Medical Nursing Division, San Francisco General Hospital,
- 1986 San Francisco, California. Responsible for four acute medical units including telemetry, an intermediate care unit, and an HIV/AIDS specialty unit. Supervision of 160 personnel. Reorganized the Division and completed several J.C.A.H.O. and state surveys.
- 1983 AIDS Clinical Coordinator, San Francisco General Hospital, San Francisco,
- 1986 California. Planned and established the Special Care Unit for persons with AIDS, Ward 5B in July, 1983 and planned and opened the expanded AIDS Unit, Ward 5A in January, 1986. Member of Infection Control Committee and San Francisco Department of Public Health AIDS Advisory Committee.
- 1981 Program Director, Forensic Psychiatry, San Francisco General Hospital,
- 1982 San Francisco, California. Responsible for two inpatient units, development of program and milieu, and supervision of staff.
- 1980 Clinical Nurse Specialist, Forensic Psychiatric and Medical-Surgical Unit, 7D
- 1983 San Francisco General Hospital, San Francisco, California. Responsibility as a primary therapist as well as staff development for all staff.
- 1979 Director of Nursing, Dodge Memorial Hospital, Miami, Florida.
- 1980 Responsible for the reorganization of the hospital and the Department of Nursing and successfully prepared the institution for J.C.A.H.O. accreditation.
- 1976 Assistant Professor, Miami-Dade Community College, Medical Center
- 1979 Campus, School of Nursing, Miami, Florida. Coordinator for the psychiatric nursing program. Also taught in community health, medical and surgical and maternal and child nursing. Participated in academic and individual student counseling and in general education and curriculum development.
- 1974 Supervisor, Dade County Department of Human Resources Health Center,
- 1976 Miami, Florida. Responsible for supervision, management and education of staff for alcohol rehabilitation programs and extended care for the elderly.
- 1972 Psychiatric Nurse, Jackson Memorial Hospital/University of Miami
- 1974 Medical Center, Miami, Florida.
- 1972 Supervisor, Jacksonville General Hospital, Jacksonville, Florida.
- 1971 Charge Nurse, Emergency Department, University Hospital,
- 1972 Jacksonville, Florida.

Professional Affiliations

American Assembly of Men in Nursing American Nurses Association American Public Health Association Association of Nurses in AIDS Care (ANAC)⁻ President, 11/92 to 11/93 ANAC, Bay Area Chapter California Nurses Association Golden Gate Nurses Association International AIDS Society

International Society for AIDS Education National Hospice Organization Nurses Coalition on AIDS Society of Nursing Professionals Fellow, The American Academy of Nursing National Catholic AIDS Network (NCAN)

Honors and Awards

Award of Merit for Outstanding Public Service, City and County of San Francisco, Presented by Mayor Dianne Feinstein, April 8, 1986.

Resolution by the Golden Gate Nurses Association for outstanding contributions to the nursing profession, May 7, 1986.

Liberty Bell award for outstanding community service, California Bar Association, San Francisco, May 23, 1986.

Who's Who in American Nursing, 1986-1992.

Award of Recognition of Service by the United States Public Health Service and the Assistant Secretary of Health, Washington, D.C., July 14, 1988.

The American Assembly of Men in Nursing, Luther Christman Award, San Francisco, California, June 23, 1989.

Nursing Transitions, National Nursing Award, New Orleans, LA, September 1989.

Most Holy Redeemer Support Group for Persons with HIV disease, Award for service, February 24, 1992.

Award for Outstanding Contributions to the AIDS Education and Training Program, California Nurses Association, June, 1993.

Activities

Shanti Project, Volunteer Counselor, 1983-1985.

University of California, San Francisco/San Francisco General Hospital AIDS Task Force, 1983-1986.

AIDS Advisory Committee, City and County of San Francisco, 1983-1987.

University of California, San Francisco, AIDS/ARC Update Conference, Member, Steering Committee, 1984-1987, Keynote Address, July 1986.

Most Holy Redeemer Parish/Support Group for Persons With HIV/AIDS. Founding Member and Co-Chair, 1985-87. Member, Board of Directors, 1985-1992.

Nurses Coalition on AIDS, Board of Directors, 1985-1987.

California Nurses Association AIDS Task Force, 1986-1989.

Advisory Committee, AIDS Project, Urban and Rural Systems Associates (URSA), 1986-1987.

AIDS Advisory Committee, Caremark, Home Healthcare of America, San Francisco, California, 1986-1987.

Mother Cares, Board of Directors, Los Angeles, California, 1986-1989.

Co-Chair, *AIDS: The National Nursing Conference*, Hyatt Regency Hotel, Hilton Head, South Carolina, November 19-21, 1987.

Member, Board of Directors, AIDS Medical Resource Group, Chicago, Illinois, 1987-1988.

Editorial Advisory Board, AIDS Alert, Atlanta, Georgia, 1987-present.

Two presentations to The Presidential Commission on the Human Immunodeficiency Virus Epidemic: (1) *Model Service delivery Systems* and (2) *Developing Psychosocial Support Systems*. January 14, 1988, Washington, D.C.

Member, American Nurses Association, Task Force on Case Management, February-June, 1988.

Member, National Hospice Organization, AIDS Resource Committee, March 1988present.

Advisory Committee, U.S. Public Health service, Health Resources and Services Administration. AIDS: Patient Care and Health Delivery Planning. Rockville, MD, May 4, 1988.

Co-Chair, *AIDS: The second National Nursing Conference*, The Stouffer Hotel, Nashville, TN, October 17-19, 1988.

Invited Participant, The Ditchley Foundation's Conference, "Handling Social Issues Affecting Public Policy, Drugs, Alcohol Abuse and AIDS: Control, Legislation, Education and Information Programs: International Action." Ditchley Park, Oxfordshire, England, November 18-20, 1988.

Invited Participant/Consultant, The World Health Organization, Global Program on AIDS, "First International Meeting on AIDS Service Organization and the Roles in HIV/AIDS Policy and Programmes," Vienna, Austria, February 28-March 3, 1989.

Invited Presenter, Vth International Conference on AIDS, *The Economic Impact of AIDS* on Integrated Health Care Delivery, Montreal, Quebec, Canada, June 8, 1989.

Co-Chair, *Third National Nursing Conference on AIDS*, New Orleans, LA, September, 1989.

Steering Committee, California Area Health Education Center System Western AIDS Education and Training Center (ETC), 1987 to present.

National Center for Nursing Research, National Institutes of Health, Priority Expert Panel, Member National Nursing Research Agenda for AIDS/HIV 1988-1989

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Planning Committee and Participant, *Nurses and the HIV Epidemic: A National Action Agenda*, an invitational workshop sponsored by the Division of Nursing, U.S. Public Health Service and the National Center for Nursing Research, National Institutes of Health, Washington, D.C., October 1-3, 1989.

Advisory Committee, California Nurses Association, AIDS Education and Training Program, 1986 to 1993.

Member, Board of Directors, Service Through Touch, San Francisco, CA, 1990-1992.

Scientific Advisory Committee, Ad-hoc member, American Foundation for AIDS Research (AmFAR), 1990 - Present.

Program Director, 4th National AIDS Update Conference, San Francisco, CA, May 19-22, 1991. Obtained grants in excess of \$75, 000 for the conference.

Chair, Conference Planning Committee and Conference Co-Chair, *4thAnnual Conference, Association of Nurses in AIDS Care.* New Orleans, LA, November, 7-9, 1991.

Member, Editorial Advisory Board, The Hospice Journal, 1991-Present.

Member, Board of Directors, National Catholic AIDS Network (NCAN), 1991-Present.

Member Conference Planning Committee, *Fourth National Catholic AIDS Conference*, Notre Dame University, Indiana, June 27-July 2, 1991.

President Elect, Association of Nurses in AIDS Care, 1992. President, Assoc. of Nurses in AIDS Care (ANAC), November, 1992 to November, 1993.

Program Director, *Fifth National Catholic AIDS Conference*, Loyola University, Chicago, Illinois, August 6-11, 1992.

Program Director, *Fifth National HIV/AIDS Update Conference*, San Francisco, CA, October 7-9, 1992. Obtained grants in excess of \$75,000 for the conference

Program Director, *Sixth National HIV/AIDS Update Conference*, San Francisco, CA, October 20-23, 1993. Obtained grants in excess of \$50,000 for the conference.

ANAC Board Liaison to conference planning committee, 6th Annual Conference, Association of Nurses in AIDS Care, Los Angeles, CA, Oct. 30-Nov. 3, 1993.

Publications

"Caring for Acquired Immune Deficiency Syndrome Patients," with Viele, C., Dodd, M. Oncology Nursing Forum, 11(3), May/June 1984.

AIDS: A Nurses Responsibility - Learning manual for educational film, with Project Team. California Nurses Association, San Francisco, California, June 1986.

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Critical Concerns for Nurses, Case Management, Interpersonal and Psychosocial Concerns. Series on AIDS, four learning modules, with Project Team. California Nurses Association, June 1986.

"Remember Who You Are." Guest Editorial. Journal of Emergency Nursing, 12(5), 254-255, September/October 1986.

"Nursing Care Plan for Persons with AIDS," with 5A Nursing Staff. <u>Quality Review</u> Bulletin, Journal of Quality Assurance, 12(10), 361-165, October 1986.

AIDS Train the Trainer Program for Health Care Providers, with Instructional Design Team. Program Guide for Trainers. California Nurses Association, California Department of Health Services, Office of AIDS, Sacramento, CA. 1988, 1989, 1990.

"AIDS 'Train the Trainer' program underway," with Schietinger, H. <u>California Nurse</u>, 83(1), 3, February 1987.

"Establishing a Therapeutic Environment for Persons with AIDS," in <u>The Person with</u> <u>AIDS, Nursing Perspectives</u>. Jerry Durham, R.N., Ph.D. and Felissa Cohen, R.N., Ph.D., Editors. Springer Publishing Co., pp. 110-125, April 1987.

"Nursing Perspectives in the Care of Patients with AIDS: Experience from the AIDS Unit of the San Francisco General Hospital," in <u>AIDS and Other Manifestations of HIV</u> <u>Infection</u>. Gary P. Wormser, M.D., Rosalyn Stahl, M.D., and Edward G. Bottone, Ph.D., Editors. Noyes Publications, Parkridge, NJ, pp. 1082-1094, 1987.

Nursing Case Management, with Fuszard, B., Bowman, R., Howell, H., Malinoski, A., and Wahlstedt, P. American Nurses Association, Kansas City, Mo. June 1988.

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Professional Presentations and Consultations

Following is a list of organizations and institutions for which Mr. Morrison has participated in educational workshops, seminars, presentations or consultations. A complete listing with titles and activities is available upon request.

AID Atlanta, Atlanta, Georgia AIDS Medical Resource Center, Chicago, Illinois American Academy of Nursing American Assembly of Men in Nursing American Cancer Society, San Francisco and San Diego, California American Hospital Association, Chicago, Illinois American Journal of Nursing Company American Nurses Association, Washington, DC American Public Health Association, Chicago, Illinois Association of Nurses in AIDS Care (ANAC) Boston City Hospital, Boston, Mass. California Association of Public Hospitals, Berkeley, California California Department of Corrections California Department of Health, AIDS Office California Department of Youth Corrections California Medical Association California Nurses AssociationCalifornia Public Health Association Caremark/Home Health Care of America, San Francisco, CA Case Management Society of America, Washington, D>C> Catholic Archdiocese of San Francisco Central Valley AIDS Team, Fresno, California

The Chicago Hospital Association, Chicago, Illinois

Ditchley Foundation, Oxford, England

Division of Nursing, NIH, Bethesda, MD

Fairmont Hospital, San Leandro, California

Florida Community College at Jacksonville, Florida

Golden Gate Nurses Association, San Francisco, California

Health Care Financial Management Association, Sacramento, CA

Health Resources and Services Administration, AIDS Demonstration Program, Rockville, MD

Hospital Council of Central California

Krebs Convention Management Services, San Francisco, California Michigan Department of Public Health

The Minnesota AIDS Funding Association, Minneapolis/St. Paul, MN Mount Zion Hospital, San Francisco, California

National AIDS Network, Washington, D.C.

The National Association for the Homeless

National Catholic AIDS Network (NCAN)

National Center for Nursing Research, Bethesda, MD

National Foundation of Infectious Diseases, Washington, D.C. The National Hospice Organization.

National Infectious Diseases Hospital, Melbourne, Australia National Institutes of Health, Bethesda, MD

The National Organization of Men in Nursing, Cleveland, Ohio.

New York Statewide Professional Standards Review Council, Inc.

New York State Department of Health, AIDS Institute

New England Deaconess Hospital, Boston, Massachusetts.

The Northern California Public Health Association.

The Norwegian Ministry of Health, Oslo, Norway.

Nursing Transitions, Williamsville, New York.

Oak Knoll Naval Hospital, Oakland, California.

Oncology Nursing Society

Oregon Department of Health, Portland, Oregon

Pacific Presbyterian Medical Center, San Francisco, California. Pennsylvania Nurses Association.

Pennsylvania AIDS Education & Training Consortium (ETC)

Phoenix Oncology Nursing Society, Phoenix, Arizona.

Prospect Associates, Rockville, MD

Quality Planning Corp., Oakland, CA

The Robert Wood Johnson Foundation, Princeton, New Jersey.

Royal Brisbane Hospital, Brisbane, Australia.

Sacramento AIDS Foundation, Sacramento, California.

San Francisco AIDS Foundation, San Francisco, California.

San Francisco Department of Public Health, San Francisco, California.

San Francisco General Hospital, San Francisco, California.

San Francisco State University, San Francisco, California.

The Schorerstichting (AIDS Foundation), Amsterdam, Holland.

The Service Employees International Union: San Francisco, Los Angeles,

Minneapolis, Minnesota, Washington, D.C., New Hampshire, Pittsburg and Philadelphia, Pennsylvania, and Toronto, Canada.

The Shanti Project, San Francisco, CA

The Sierra Foundation, Sacramento, CA

The Sisters of St. Mary Health Care System, St. Louis, Missouri.

St. Elizabeth's Hospital, Lincoln, Nebraska.

St. Vincent's Hospital, Sydney, Australia.

Swedish Hospital Medical Center, Seattle, Washington.

U.S. Department of Health and Human Services, San Francisco, California.

U.S. Public Health Services, Health Resources and Services Administration, Rockville, Maryland

United States Army, Fort Polk, Louisiana

University of Southern California, Los Angeles Medical Center

University of Amsterdam, Holland and the Academish Medum Centrum, Amsterdam, Holland.

University of California, Berkeley, School of Public Health

University of California, San Francisco, Schools of Nursing and Medicine, San Francisco, California.

University of Delaware, Academy of Sciences, Dover, Delaware.

University of Minnesota, St. Paul, MN

University of Pittsburgh, Pittsburgh, PA

University of Texas, School of Nursing, Arlington, Texas.

Whitman - Walker Clinic, Washington, D.C.

The World Health Organization, The Global Program on AIDS, Geneva, Switzerland

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SAN FRANCISCO GENERAL HOSPITAL AIDS INPATIENT UNIT BACKGROUND

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San Francisco General Hospital opened the first 12 bed AIDS inpatient unit in the nation in July 1983. The original staff of 12 nurses who chose to work in the Medical Special Care Unit 5B (now 5A) received intensive training in the treatment of AIDS, with special emphasis on the patient's need for psychosocial support and specific clinical needs related to the disease.

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In March 1986 San Francisco General expanded the AIDS unit to 20 beds, although the SFGH AIDS census usually ranges from 25 to 30 patients. The unit staffing now consists of 24 full and part time nurses and nine half-time Shanti counselors. A clinical nurse specialist and two social workers see patients both on and off the unit. Medical care of the hospitalized AIDS patient is under the direction of Dr. Merle Sande, UC-San Francisco professor and chief of medicine at SFGH.

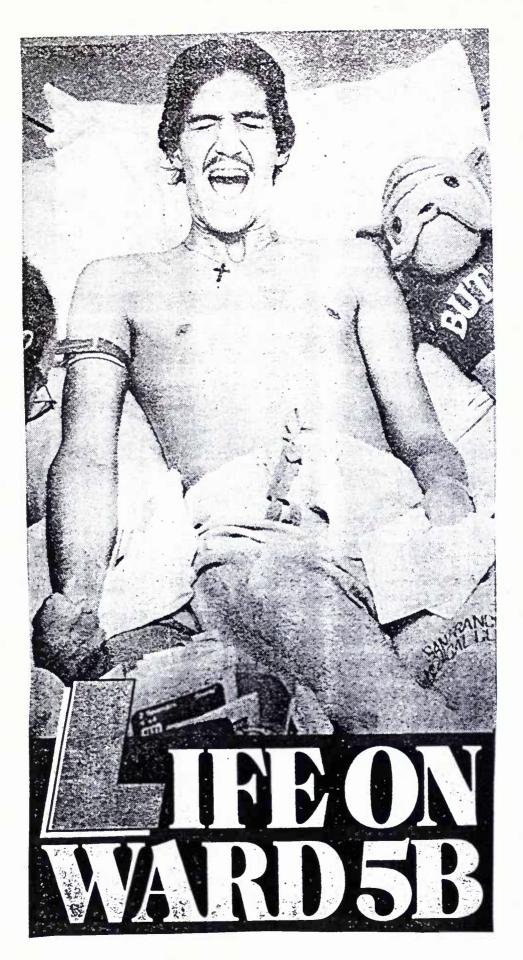
Cliff Morrison, RN, CS, MS, was the original clinical coordinator and principle designer of the unit and served as director of Medical Nursing and clinical coordinator of AIDS at SFGH. At present he is project director for a California Nursing Association grant and clinical consultant to the San Francisco Department of Public Health AIDS Activity Office. Michael Clement, MD, is now the liaison between the inpatient unit 5A and clinical services at SFGH.

Morrison has described how the unit was needed for the large number of AIDS patients scattered throughout the hospital. SFGH treats more than half of the AIDS patients in the city. The AIDS unit has made it possible to coordinate adequately the quality of care, centralize resources and staff expertise and to deal with the many patient care issues confronting the staff

The unit was designed using a nursing model that provides humane and quality care for the AIDS patient. From the onset, the main focus of the hospital was to develop and implement discharge planning, as it would be more cost effective to treat patients at home as outpatients, in hospices or at long-term care facilities.

Daily cost for home care averages \$100 and the daily cost at a long-term care facility is \$300 compared with \$800 a day in the hospital. Hospital costs at San Francisco General average \$878 per day or \$29,000 per patient lifetime compared to the national average of \$140,000. (The Robert Wood Johnson Foundation, a national philanthropy, is making a commitment to provide \$17.2 million to ten cities in the country with the highest AIDS case loads if they offer humane and less costly health services for AIDS patients modeled after the San Francisco program.)

Ward 5A is also notable for its high level of community participation. An active group of volunteers enhances the services provided on the unit. Others provide entertainment and special dinners on weekends and holidays for the patients.



BY RANDY SHILTS

hanteuse Sharon McKnight tugged her black and white feathered boa over the web of clear plastic tubes threaded into one patient's arm as she stooped to examine the light blue hospital gown of another.

"Love it," cooed McKnight, affecting her Bette Davis accent. "It looks designer."

"See the Dior label?" parried Nick DiLoreta, tugging the gown around his neck like a precious mink.

"San Francisco General-Hospital," gushed the entertainer, fingering the gown: "Yes, yes. This is the only place where I like *not* playing to a full house."

Nobody was insulted; McKnight was giving her little performance in Ward 5B of San Francisco General Hospital — the AIDS ward.

McKnight, a performer with enormous popularity in the gay community, was singing here that cold, drizzly night because she knew that most of the patients would never get to a night club again. More people die in 5B than in any other ward in the hospital.

The outbreak of Acquired Immune Deficiency Syndrome has been so virulent that a malady unimagined just four years ago and unnamed until two years ago commands its own 12-bed ward now. The ward exists in large part because AIDS had so much terror and stigma associated with it that patients weren't getting decent treatment elsewhere. Everyone was too scared of them.

As stage for the most frightening epidemic since polio, the AIDS ward has provided the setting for many anomalies. A fiercely committed nursing staff works 12-hour shifts daily, knowing its work will not save lives but will simply make death comfortable. All members of the ward staff insist they would work nowhere else, even though the job gets so jarring that nurses meet twice weekly in encounter groups to work out their anxieties.

The texture of life and death in Ward 5B is described most succinctly in the nightmares of the patients.

"You'll talk to somebody here one day and they'll say that they're feeling better," Bruce says. "The next day you'll see the nurses taking the sheets off the bed. You don't have to ask what happened because you know."

Often fatigued and sometimes depressed, Bruce spends most of his time watching television. Much of what he sees doesn't make sense now. The commercials about retirement accounts and pension funds are particularly painful. A normal 30-year-old single male like Bruce should expect to live 43.2 years more, according to insurance actuarial tables. But the average victim of PCP can expect to live 10 months after diagnosis; few have survived for longer than two years.

"This is like being on Death Row," Bruce sighs. "But it's worse. You don't know when it's going to happen or how it's going to happen. Will it be the pneumonia or some other disease you've never heard of? You know it probably will be painful. At least on Death Row you know the date and that it's going to be pretty quick and painless." hen Cliff Morrison, a 32-year-old clinical nurse specialist with a background in hospital administration, suggested a special ward for the soaring number of AIDS patients early last year, hospital administrators told him he was crazy. He was told that nobody would want to work in a ward full of dying gay men. Even at San Francisco General Hospital, where AIDS patients were treated better than just about anywhere else in the country, some nurses were bridling at handling the ever-growing AIDS caseload. This was the very reason the city needed a unit to treat AIDS patients exclusive-

ly, argued Morrison. Ward 5B exists because Morrison won his argument.

Three times as many people applied to work in the ward than Morrison needed. Drawn largely from registered nurses experienced in emergency room and intensive care work, the 5B staff is one of the most highly trained teams in any San Francisco hospital, operating in one of the most unconventional wards in California medicine. A determined administrator, Morrison has a distaste for the traditional pecking orders and hierarchies of hospitals.

"The traditional ways wouldn't work here," he says. "Normally, the doctors rule over the nurses and the patients have little involvement in their own care. They don't want visitors or other outsiders in the ward. But we're writing the book on AIDS care here.

"Nurses sometimes know more than the doctors about this; it's not something the doctors have studied in school. The patients sometimes know more than the nurses. And we encourage visitors. They're a tremendous asset in keeping up the will to live."

Painted in cheerful yellows and oranges, and overgrown with house plants, 5B is an informal place. Patients and staff chat about treatments over coffee and doughnuts in the morning. Gay nurses sometimes drop in from other units. The conversations sometimes evolve into high camp, eerily punctuated by painfully long coughs that echo from the rooms of the many pneumonia patients.

by should I keep from identifying with the patients?" wonders Bill Barrick, a gay registered nurse who transferred to 5B from the clinic at the county jail. "Of course I identify with them. They're my age; I knew some of them before they got here. We're told that it's not professional if our emotions show through. But we couldn't work that way in this ward. It's too intense. To me, working here has gotten me in touch with what nursing was in the beginning — personal care given by an extended family."

Many patients of Ward 5B say night supervisor Cathy Juristo is the most reassuring presence for them. A gray-haired grandmother, Juristo counts her six months in the ward as the most rewarding work in her 37 years as a nurse, even though she has confronted an unprecedented level of grief.

"It makes me feel like a better person to work here; you can do so much to make their stay more comfortable," she says. "They might not get that if you don't give it to them. They're such wonderful guys, they deserve it." The ward also receives community support unknown to other units in the hospital. Every day, Martin Cox, who has a half-dozen AIDS-related diseases himself, troops from room to room with newspapers, donated pastries and compassion for the dozen patients who normally lie in the ward. Entertainers — McKnight, for example — donate time and money for the AIDS Patient Fund, which finances small comforts

for the sometimes-destitute patients. Volunteer grief counselors spend hours with patients.

"This is a part of the gay community that doesn't get publicity," says nurse Barrick. "The level of support is astounding."

The ward is dealing with avant garde issues of medical care, most notably the question of when 2 patient has a right to stop fighting and die. "No Code" is the medical term that sums it up. "No Code" means that no "extreme measures" be taken to preserve a life. Patients go "No Code" in 5B more often than in any other place in the hospital.



eotis McMather holds the distinction of dying faster than any of the unlucky men in 5B.

A native of the hills of southern Virginia, Deotis had lived a somewhat seamy life, hustling tricks and shooting drugs in the Tenderloin. Last April he noticed purplish bruises all over his body. Not knowing anything about medicine, Deotis had no way of knowing that his immune system had gone haywire and had stopped producing the cells called platelets that make blood clot. Instead of clotting, his blood began to leak from his capillaries with each bump he suffered; the little bruises were external evidence of the deficiency.

By late October, a friend told him his back was covered with them. Deotis himself knew he was very sick; he checked into the hospital for tests. The news that he was getting tested for AIDS prompted his roommate to have Deotis' belongings packed and sent

off to a friend's house.

"Never come back here again," the roommate said.

"I guess it shows you who your friends are," said Deotis stoically.

A week into his hospital stay, the doctors determined that Deotis had ideopathic thrombocytopenic purpura, another one of the bizarre diseases that are associated with AIDS. Because this had inflamed a good portion of his abdominal organs, doctors cut out McMather's spleen and parts of his liver and stomach.

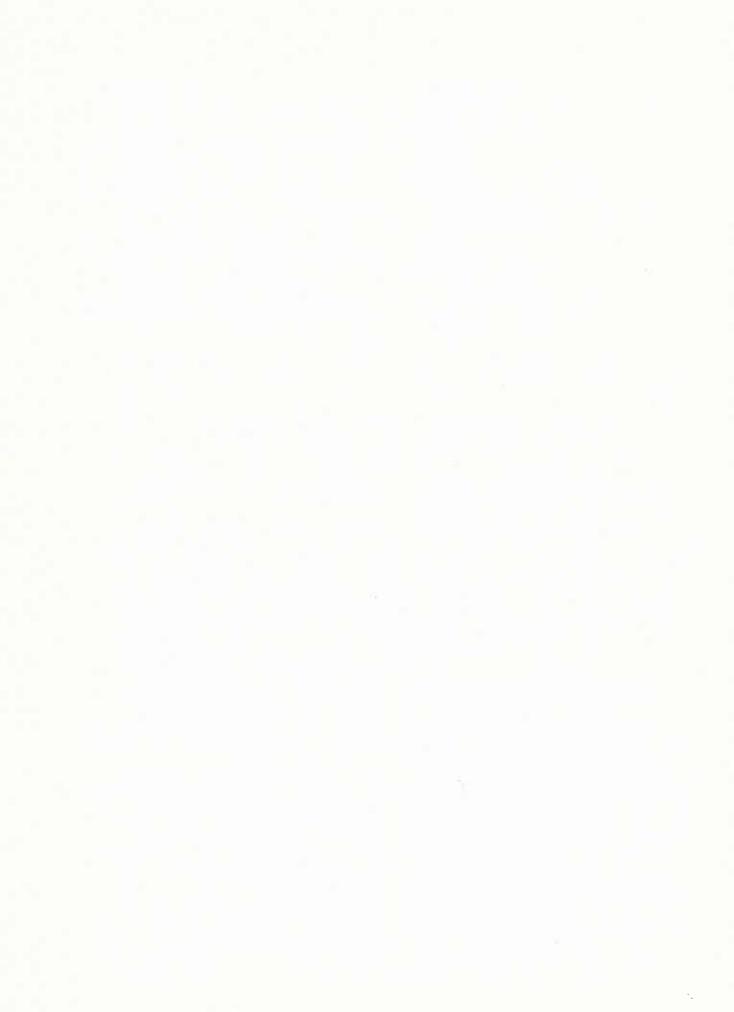
About two weeks later, Deotis' already sad disposition turned grim. "I don't want to be around and be a drain on other people," he said. His condition deteriorated and he was put on a respirator. Then, within hours of the deaths of two other 5B patients, Deotis asked nurses to take out the breathing tubes. At the age of 27, Deotis McMather quietly died. "We can make death comfortable," says Morrison.'They'll fight and fight and fight. And then it comes to the point that they'll say, I just can't take it anymore,' and then, they'll die."

he brisk weeks of winter brought bad times for 5B. With the damp, cold weather, painful *Pneumocystis* pneumonia flared in the lungs of many AIDS patients. The beds of 5B were full. In one 24-hour period, three men died on the

Bruce Schneider's voice barely carries over the hum of traffic on the freeway a few hundred feet from the window of his corner room.

"Every day, you watch television, for some word, some sign that maybe they've found something, some miracle cure, some quick fix," he says. "You're on Death Row here, but maybe you'll get a reprieve from the governor. Maybe you'll get another chance."

ward.



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The Municipal Court



San Francisco, California

HERBERT DONALDSON, JUDGE

March 26, 1984

Geoffrey Lang Executive Administrator San Francisco General Hospital 1001 Potrero Avenue San Francisco, California 94110

Dear Mr. Lang,

I am writing you about a concern of mine which I have which was brought home when I was this past week visiting a friend of mine who is an AIDS patient in Ward 5B. In talking to the staff there and to my friend, Mr. Palmatier, it is apparent that Ward 5B is not sufficiently large to handle the AIDS patients.

I learned to my suprise that Ward 5B holds 12 patients and in fact this past week San Francisco General had 25 patients, which means that a larger percentage were housed outside Ward 5B. Ward 5B has many advantages. The staff is, as I understand it, entirely volunteer. Their handling of AIDS patients is extremely sensitive. Mr. Palmatier tells me that when he was housed in another part of the hospital before a bed became available in 5B it was the Chief Nurse of the ward who was able to respond to him, the other employees not wishing to have contact with an AIDS patient.

The number of AIDS cases in San Francisco is continuing to increase and if what I read in the papers or hear from my medical friends is accurate will continue to do so for the foreseeable future. The number of patients which S.F. General is going to have to house is going to continue to increase as well, because as the AIDS patient progresses there is an increasing need for hospitalization. Additionally there are not sufficient facilities organized to accommodate the large number of seriously ill AIDS patients.

I have been up to Ward 5B a number of times, not only to see Mr. Palmatier but before to see other friends of mine who have been hospitalized. The care given in Ward 5B is outstanding and I believe no other hospital gives such centralized care to AIDS patients.

I believe it is imperative that the ward for AIDS patients be expanded. I am not familiar enough with the hospital to know whether there is available unused hospital space, but if there is this should be utilized. I realize that additional staffing would be required, including hiring nurses and physicians to supple-ment the existing staff and that this would increase the cost to



The Municipal Court

San Francisco, California

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HERBERT DONALDSON, JUDGE

your hospital's budget. The fact is that it is necessary, and planning should be instituted now so that an emergency does not arise.

San Francisco has the reputation of giving at S.F. General the finest care to AIDS patients which is available. To keep this high quality service available, now is the time to expand the facilities for housing our AIDS patients.

Very sincerely yours,

HERBERT DONALDSON

BC: Paul Volberding, M.D.

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DIANNE FEINSTEIN

September 27, 1984

OFFICE OF THE MAYOR

SAN FRANCISCO

Staff at Ward 5B San Francisco General Hospital 1001 Potrero Avenue San Francisco, California 94110

Dear Staff at Ward 5B:

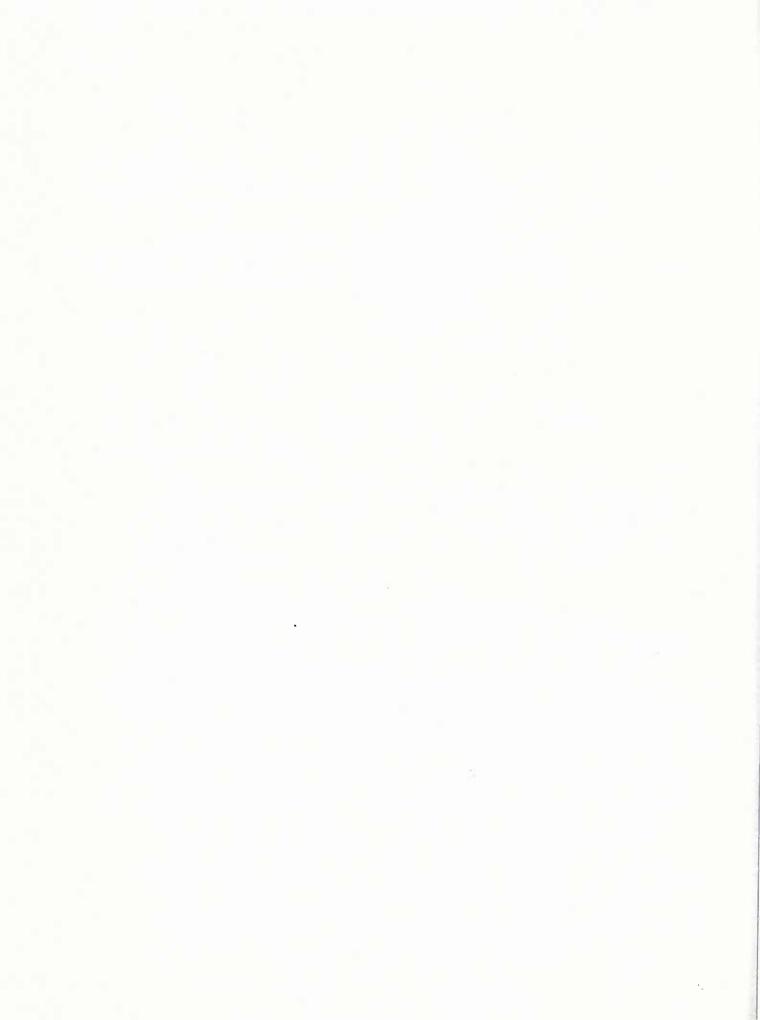
I have received your September 21 letter regarding expansion of inpatient services for AIDS patients at San Francisco General Hospital.

Please be assured that I am aware and concerned about the needs of AIDS patients at San Francisco General and elsewhere. I will be reviewing the Department's plans to cope with anticipated future patients. I very much appreciate your concern for your patients and your dedication to your jobs.

Sincerely yours, 2514 Dianne Feinstein Mayor

DF/MK:la

ec: Dr. Mervyn Silverman, Director of Health



City and County of San Francisco

Department of Public Health

San Francisco General Hospital Medical Center

Merle A. Sande, M.D. Chief, Department of Medicine

April 15, 1987

Dear Dr. Sande,

at:

We would like to thank you for attending the March 25th meeting during which 5A expansion was discussed. We are pleased to have had the opportunity to establish a much needed dialogue between the parties involved in the future of 5A. We felt our input was well received and trust that we will continue to play a role in the decision-making process. We are writing this letter to reiterate the key points addressed.

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We believe that the major issue affecting the care of AIDS patients and indeed, all patients - is the severe shortage of nurses at San Francisco General Hospital. We have been unable to maintain adequate staffing to care for the twenty patients presently on 5A, which makes it questionable whether we will be able to staff the proposed enlarged unit. We realize that a way must be found to address the needs of <u>all</u> AIDS patients at SFGH; we firmly believe, however, that 5A must be left intact as a twenty-bed unit if it is to remain a model of care. It is imperative that we continue to be a center of excellence where those patients with the most complex and critical medical and psychosocial needs can come to receive the high level of expert care which has become our standard on the AIDS Special Care Unit.

Adding eight beds to 5A will not have any significant impact on the long range problem of rising numbers of AIDS patients at SFGH. Other more effective long range plans and options must be considered. If AIDS patients are to be doubled we suggest that this occur with less acute patients on other units rather than with the more seriously ill patients in need of the kind of comprehensive AIDS care provided on 5A.

The doubling of patients on 5A would make it impossible to continue to provide our current high level of care. Families will not be able to stay with their loved one if there are two patients in a room. The confidential and intimate counseling services that are an essential component of the care we provide will be seriously compromised. Pairing a newly diagnosed patient with a dying or gravely ill patient could be severely detrimental to that patient's physical and mental well-being. Exorbitant amounts of time and energy will be spent moving patients around to prevent such situations or to maintain infection control standards. It would be easier to double up patients on other units and transfer them to private rooms on 5A as needed.

We have developed an internationally recognized and acclaimed model of care for people with AIDS. We serve as a resource center to people with AIDS and health care providers at SFGH, to our community and to communities throughout the world. We will no longer be able to accomodate the vast numbers of visitors and media coming to 5A if more patients - along with their families and friends - are added to the unit.

5A has proven to be an invaluable training center for physicians and other professionals who provide care to patients with lifethreatening illnesses. We offer a place where patients can die with dignity and where the care of dying patients can be a positive experience for health care providers. We have witnessed many physicians who, through their experiences on 5A, have grown tremendously in their ability to care for such patients. It is unfortunate that all dying patients and patients confronting life-threatening illnesses do not receive this type of comprehensive care. Taking away from the services we provide to our patients, however, is not the answer.

While we firmly believe that all dying patients deserve this level of care, it must be recognized that AIDS patients face more complex issues than general oncology patients. AIDS is an infectious disease with 100% morbidity, which has resulted in widespread fear and hysteria in the community. In San Francisco, our population of AIDS patients is still over 95% gay and sexuality issues become an additional factor to take into consideration in providing care. Our patients often do not have traditional support systems. Many have been rejected by their families for revealing their sexuality. Others who have not "come out" to their families are often forced to do so when diagnosed with AIDS, resulting in the overwhelming fear of losing family support at the time when it is most needed. The support systems our patients have developed are often not validated by our society or by traditional hospital rules. Often legal counseling is needed to guarantee that their rights and wishes are honored. For heterosexual I.V. drug users, privacy is also a primary consideration in dealing with issues of substance abuse.

For the person with AIDS whose support system is also stricken, their situation may be even more tragic. Many of our patients have already experienced the deaths of lovers and friends and find they must face death alone while dealing with their grief over multiple losses.

Our population is generally in their 30's, lives alone and does not have children or families to care for them upon discharge, as many oncology patients do. We spend a great deal of time in discharge planning in order to find suitable housing and support. We are already facing increased acuity on 5A since, as patients live longer, the virus causes more damage to the brain cells. We now care for greater numbers of patients with severely impaired mental status. In addition, as more treatments are administered on an outpatient basis, the acuity for inpatients correspondingly rises.

Because we utilize community resources and encourage family and friends involvement in patient care, an increased census of twenty-eight signifies more than just eight additional patients: it also means more doctors, nurses, social workers, volunteers, etc. as well as eight additional sets of families and friends who will not be able to stay in the patient's room. This increase will add to the congestion of our already overcrowded hallways and lounge.

We have been instrumental in the development and success of this unit and feel adamant that we must be involved in decisions affecting its future. We have all chosen to work on 5A because we are dedicated and committed to caring for AIDS patients. Because so much of our hearts and souls has gone into creating a model of excellence in the care of AIDS patients, most of us would not be able to stay on 5A to give less quality care while watching a dream die. Many of us would leave, as some have already chosen to do.

In conclusion, we would like to again emphasize that the current nursing shortage is already compromising care of AIDS patients and all patients at San Francisco General Hospital. Once staffing needs are more adequately met, we would like to see the following options considered in the place of the projected eight-bed expansion of 5A:

- Doubling AIDS patients on the other units rather than on 5A;
- Opening the transfusion/I.V. meds unit in the clinic building as suggested;
- 3. Exploring the possibility of a "cap" on our AIDS inpatient census with the understanding that you and Paul Volberding are expediting referrals of AIDS patients to other physicians city-wide in your roles on the Mayor's Physicians AIDS Advisory Committee;
- 4. Using 4C beds on a temporary basis until resident sleeping quarters are constructed in the basement and subsequently opening 5B as a second AIDS unit;
- 5. Pressuring the city to fund an increase in the number of extended care beds available to facilitate earlier discharges.

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Thank you for the dialogue and exchange of ideas; we look forward to our next and subsequent meetings.

Sincerely,

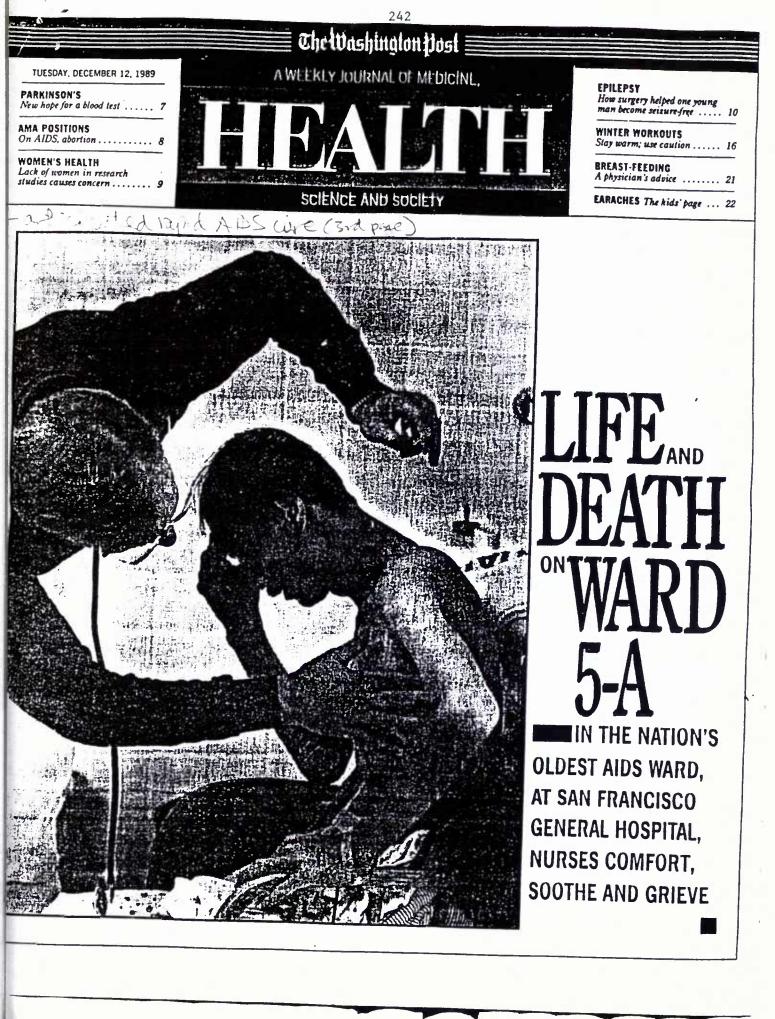
The Staff of 5A AIDS Medical Special Care Unit

/cv cc: Brenda Lauer Director, Medical Nursing Division

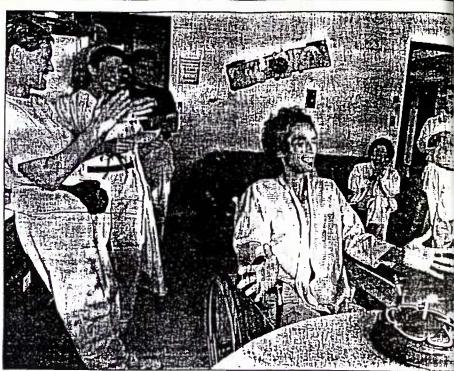
> Judy Spinella Associate Administrator for Clinical Services

Phillip E. Sowa Executive Director.

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Michael Gomes is surprised by nurses with a party on his birthday.

OLDEST AIDS WARD. AT SAN FRANCISCO GENERAL HOSPITAL, NURSES COMFORT, SOOTHE AND GRIEVE

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Nurse David Denmark helps a patient.

By Jans Meredith Adams Send to The Reductor Post

SAN FRANCISCO At age 30, Susanna Kiely has seen enough despair and death for a lifetime, but that is not what concerns her now. This morning she strides into Anthony Ragusa's hospital room with fresh sheets and towels. She has promised him a bath. "Do you want some bath oil?" she ssks. "Oh yeah," he says.

Ragusa, 43, leans on a cane. Kiely is by his side, wheeling a portable oxygen tank that connects to his nose. Together they move down the ball to the bathtub room.

The AIDS ward at San Francisco General Illopital, where Kiely works, is the oldest inpatient AIDS ward in the nation. Since 1983, the grief of this city has passed through its doors; of the 4,609 San Fran-ciscans who have died so lar because of AIDS, more than a quarter were cared for by the nurses here.

For these nurses, as for the thousands of AIDS caregivers across the country, the vastness of the epidemic translates into the particular: helping a bed-ridden patient into his first both in three weeks, listening to a woman who is afraid to tell her children she is going to die, changing the sheets six times a day for a man with chronic diar-rhea-and joking with him about it.

There's nothing I can do about the AIDS virus, but there is something I can do in the work I do," says Kiely. "When I'm with a

patient. 1 think, 'What are we doing now?' Not, 'Are you going to die? Are you never going to go home again?' Thave my moments," she says simply. 'I wonder, 'Where did AlDS come from? Why hum? Why now? Why, why, why? All those why questions. I deal with it. It's part of my bl. have a wordersite that is reactionable job. I have a profession that is applicable, that takes away the helpless feeling. I'm doing something. On the ward, Kiely and Ragusa walk hack

down the hall to his room. "I leef hrand-new when 1 get a bath," says Ragusa, climbing into bed, his dark hair and mustache neatly combed.

Ile is the most well of her three patients today, recovering from pneumocystis carinii preutionia, a once-rare form of pneumonia with AIDS. After losing 30 pounds in three weeks, he is maintaining his weight.

"When I first came in," he says, leaning back on a pillow, "I was depressed, and a nurse came in and hugged me and consoled me and let me cry. When I get better and out of here, I want to come back and he a volunteer," Kiely moves next door to see Vern,

Kiely moves next door to see Vern, whose lamily asked that his last name not be disclosed. He is fighting posumorystic carinii, diarthea, wasting syndrome and cy-lomegalovirus retinitus, which can cause blindness. It is 4.3. Taree weeks from this day in the hospital he will be dead. As Kiely comes in, he 'cares his arms in front of him, trying to g asp something in the air. "It's claustrophooic," Kiely says of

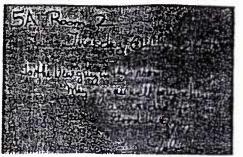
the oxygen mask that keeps him alive. The machines in the room make a noise like the filter on a swimming pool. Vern roughs painfully, as if he is literally coughing his guts out.

"Waut me to clean some of that out of your mouth?" Kiely asks. He says something: from behind the oxygen mask, his voice sounds like it is under water. She pauses a moment and strokes his forehead with her hand. "Ukay. arectheart," she says.

She moves efficiently around the bed As she walks, she smooths his sheet. She pulls a tube from the wall and suctions mucus from the back of his mouth that he is too weak to



FROM THE BEGINNING. THE AIDS NURSES **DECIDED THEY WOULD** TOUCH THEIR PATIENTS, HOLD THEM AND CRY WITH THEM.



A former patient leaves a note for the new occupant.

ough up. The day before, because his swal-owing reflex was weak, she put a tube into his nose to connect with his stornach. "I talked with his lover about it." says

Kiely. "Ite said it was okay for supplements and medication but not for it to be lifesustaining."

When she turns away, Vern swings his legs up to the bedside railing. They hang there, stick-thin, bare except for his black socks; he is too weak to pull them over.

Vern, you can't get out of bed." Kiely says. I know you feel like you need to but you can't." When he was on another ward waiting to be transferred to Ward SA, he got out of bed, fell and cut his head,

She steps into the hall and picks up a teleshone to call for medicine for Vern. While the is on hold, she files her nails and leans over to look into the room, to see that he's ill right. She puts the medical order in, langs up and gors in to change all his tub-ing. When she is through, she tics restraints from his wrists to the metal railings on the bed. "I hate doing this," she says.

A the contract of the

te moves pest door to sponge the back ind shoulders of Robert Jones while he sits on a chair commode. She scrubs his hairy chest and fluffs it dry with a towel. AIDS lementia has made him disoriented. Kiely vites information on a board across from its bed to selp him. She writes, "Hi Bobl You are in Room 5A3 at San Francisco Gen-ral flospital. Your muse is Sue." She writes the date in big letters. Underneath, a friend of Jones has written, "I LOVE YOU!" and signed bin name. Richard and signed his name. Richard.

Jones is too weak to stand up. When he vants to go back to bed. David Denmark, anther nurse, comes to help lift him. He tells lones to lean forward and grab hold of him. "Give me a hug," says Denmark. Jones

reaches up. "I usually charge for these," says

Denmark. "Oh, teally?" says Jones.

Kiely life Jones' legs, and they swing him no bed "Aren't we butch," says Denmark. "Ever so," says Jones. Within six weeks,

It is 11 a.m. and Kiely is four hours into

what will be nearly a 13-hour shift. When she gets home at 7:45 p.m. or so, she will follow her usual routine. Her four cats-Sarah Mae, Anastasia, Sputnik and Titlywill meet her in the yard and walk her to the front door. Going down the hallway,

she'll kick off her meakers and hit the play button on her answering machine. She'll sit down in the living room and read the mail. She will think about taking a long, hot bath. This is the last day of her three-day work week. On her four days off, she likes to make hand-built ceramic plates and objecta and visit frien.14. "It's really important to focus on life," she says.

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Setting a World Standard

"From the very beginning, it was the best place 1 had ever worked," saya Stephen Keith. He was part of the original staff of 12 nurses when the AIDS ward opened on July 25, 1983, on the fdth floor of San Francisco General, a county hospital mandated to pro-vide care for the poor, "We were setting the standard for the world."

Keith, like all of the nurses, dresses cas-"I like it here," he says, "except for days like today." He leans forward and puta his head in his hands. "Bob'a in the I.C.U." Robert Adrian, who has been a nurse on the ward since it opened, is in the intensive care unit at another hospital with disseminated tuberculosis, a condition caused by AIDS.

"Two of the original 12 nurses are dead," says Keith. One, a woman in her fifties, died of breast cancer; another, a man of 40, died of AIDS. Two weeks later, Robert Adrian, 33, also will be dead. When Keith began to work on the ward, he recalls. We thought that in five years we were going to know what this is and

have drugs to cure it and be out of a job Now, he says, "it's been so long since I've

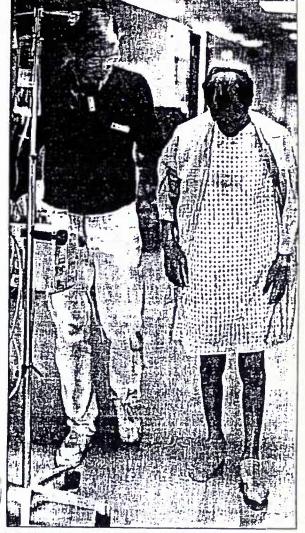
gotten my hopes up." When the ward opened, the nurses wanted to keep a record of what was happening. On the pages of a red scrapbook, they wrote the names of patients who died and beside the names, a memory:

Elizabeth, found (deod) in front of her apartment building, Mom of 3. Bill, sober and clean & years.

Alfonso, saw the Pope, wanted to see family ence mere.

ly once more. Lee, met Lie Taylor, high point of life. Wayne, drank Drana, threw himself thru window, survived to comment, "I just had a had doy.

Now there are 1,062 names and counting. Keith still writes in the book, but there See AIDS WARD, Page 14



Nurse Stephen Keith helps Mark Garaveale out of bed for a brief walk.

GAY RELATIONSHIPS ARE HONORED, AND PATIENTS ARE GIVEN THE POWER TO NAME A 'SIGNIFICANT **OTHER' WHO WOULD BE INVOLVED IN MEDICAL** DECISIONS.

AIDS WARD, From Poge 13

are so many patients and deaths, it's hard to keep track

Keith began working with AIDS patients before the AIDS ward was established, at a time when the acronym AIDS, for acquired into use; the discate had been known as Gay-Related Immune Deficiency, or GRID. The human immunodeficiency virus (HIV), believed to cause AIDS, had not yet been identified.

Some food servers were afraid to enter the rooms of ALDS patients and left food trave for them in the hall, he remembers. Some doctors and nurses suited up in masks and gowns hefore going near a person with AIDS. Patients (in San Francisco, the majority were gay men) fell ill with horrendous combinations of infections, for which the medical profession had few

treatments to offer. "People really didn't want to come onto our ward," Keith recalls. Like all of the staff on the ward, he volunteered to work there.

The inpatient AIDS ward at San Francisthe upsuch ADS wald at San Francis-co General was the first to group ADS pa-tients together, to consolidate the medical expertise they required. I was against it," recalls Donald Abrams, assistant director of ADDS activities at the hespital. "My initial concern was that it would be like a sanitarium or leper colony.

"Most people will agree now it's one of the more pleasant places to visit as a vis-itor, patient or health care provider," he says. It's a center for patieota to be comfortable in and call their own."

The nurses are the constant figures on the ward: doctors affiliated with the medical school at the University of California at Sao Francisco rotate through every month. As a result, saya Abrams, "the nurses provide a lot of teaching about AIDS and AIDS patient management to student doctors and doctors at higher levels."

Cliff Morrison, a nurse and clinical AIDS coordinator at the hospital at the time, re-jected the hierarchical "medical model" of matient care and structured the ward so that nurses could be more autonomous. In selecting the staff, he looked for nurses "who weren't



Cover Story

satisfied with the way patient care was being delivered, who wanted professionally to make more decisions." He also wanted nurses who were confortable around gay men and who were willing to examine and express their feelings about their own mortality.

As part of an intense, one-week training, the arses imagined their own deaths and talked rout why they wanted to work on the ward. Of the 15 stall members-12 nurses, one head nurse and two ward clerks-about half were gay. In the first two years, none of the

e J

nurses left the ward, a phenomenon "unheard of at San Francisco (general," says Morrison. "The other to longer boasts the lowest attri-tion rate in the hospital, acknowledges Alison Moed, head nurse on the unit. "There is only a certain period of time you can do this work." certain period of time you can do this work." Four beds out of 20 on the ward ate empty because there aren't enough nurses in care for patients, she saya. Nurses earn \$35,000 to \$40,000 a year at the hospital. The shortage on the ward reflects the nationwide nursing shortage, she says, as well as turnover of longterm staff.

For some nurses, there also is fear of accidental blood-to-blood contact with the AIDS virus. One nurse at San Francisco General accidentally stuck herself with a needle she had used with an AfDS patient; her blood "converted" and tested positive for antibodies to HIV, meaning that she has a good chance of coming down with the dis-ease herself. When that happened, says Keith, "people left the ward." That nurse has left her job.

The patient population also has changed on Ward 5A; where it was once dominated by gay men, now 20 to 25 percent of patients are intravenous drug osers. All of the patients, whether middle-class gay men or poor intravenous drug users, are "very acutely ill" when admitted. Moed says, because patients who are not as III have a to outpatient and other forms of care that didn't exist in 1983. The result is an in-creasingly attended environment for nurses.

"A resi focus for us in setting up the ward was, how do you plan to take care of your-self to be able to do the work," recalls Morrison. A support group for staff formed, and exercise, art work, therapy and vacations were encouraged, he says. The nurses voted on the schedule they

whuld work: an unconventional 12-hour shift, three days a week, with four days off Most important, in 1983, when information on how the virus is transmitted was still incomplete, the nurses made a decision to wsik through their fears. They believes what early medical atudies showed-that the disease was transmitted through bloo and not through casual contact. Later th medical theory would be confirmed that the virus was also transmitted sexually. The nurses were instructed to wear glove when handling bodily fluids.

From the beginning, they decided they would touch their patients, hold them an cry with them. I don't think by showing emotion we're unprofessional," says Mor rison. "The question is how to be human without going too far. If you cut off the flow of emotion, you won't last long."

"We were really feeling the appreciation of the patients and their families," says Keith. "In the early days, they were getting so much rejection outside the hospital. We were support ing them. We were like family to them." Gay relationships were honored, and pa

tients were given the power to name a "sig ulicant other" who would be involved in medical decisions. Visiting hours were shol ished; friends and family were welcome 24 hours a day.

Visitors from around the world came to see the ward, including then surgeon gen eral C. Everett Koop; Eliusbeth Kubler-Ross, author of "On Death and Dying:" and Elizabeth Taylor, actress and AIDS lund raiser. Many of the roughly 50 specialized AIDS units now in place at hospitals sroun the country, including the B. Frank Polk AIDS inpatient unit at Johns Hopkins Hospital in Baltimore, are modeled on Ward SA.

510 Nurse Diane Jones looks through a scrapbook of photos of potients on Ward 5-A.

and the statement of the st



urse Susanna Kiely makes a patient more comfortable

The way I know I'm not burned out is that people still get to me," says Keith. A ew months ago, the lover of a patient was elephoned and told to come in quickly, the ratient was close to death. When the lover arrived, he walked into the hospital room and found the man dead.

"Ife came out into the hall and grabbed The came our into the name and gradoed me and said. "Something is very wrong," recalls Keith. "I wasn't even the patient's surrae. As soon as I walked into the room, I new he was gone." The lover stayed by the sedside and sobbed. The next day, he came back to attend a family support group and prought the nurses a box of chocolates. He ought Keith again. "He told me he had things he still wanted

the torus me in no trans ne stull wanted to say to his lover that he was never going o he able to say because he was dead when is got there," says Keith. "I broke down crying in the hall."

Before Keith started to work in the AIDS word, be had never hed a potent die ou his hilt. "I haven't known a lot of people who have died of AIDS in my personal life," Keith eave. Its is a gay men and his own health is good, he says; he has tested neg-tive for antibodies to HIV.

"I don't have any control over whether people live or die," he says. "I do have con-

trol over how comfortable people are. I can bring a glass of juice to someone whose lips are cracking and dry. That patient will come hack and say, 'I remember that day you came and got me something to drink.'

"When we die and go to wherever we go," says Keith, "we're sure going to have a lot of wonderfal people there."

A Certain Detachment

In the beginning, it's very overwhelming says murse Diane Jones, who spends her offduty hours doing political work involving wo-men's issues. She was one of the original staff on the ward and worked there for six years

on the ward and worked users for any years before transferring to pediatica. "You die with every patient who touches you as a person. Then, at the six-month point, you kind of bottom out around it," she says. "You get angry and depressed and you leave or stay. If you stay, then you stop dyleave or stay, it you asy, this you can't be ing with every patient because you can't be an effective provider. You get a certain kind of detachment that allows you to go on.

This detachment, she saya, "is not equal heine uncarlor, uninvolved or withto being uncaring, uninvolved or with-drawn." It is accepting the reality of the epidemic. "As soon as a body is taken away, there is another patient in that bed."

The emotional charge of the work chal-

'I DON'T HAVE ANY CONTROL OVER WHETHER PEOPLE LIVE OR DIE. I DO HAVE CONTROL OVER HOW COMFORTABLE PEOPLE ARE.'

Stephen Keith, Nurse on Ward 5A

lenged her. Jones remembers one young man on the ward who had been an actor and a mod-el. His face had become severely disfigured by Kaponi's sarcoma. A purple lesion covered his nose, and his checks are so wrolen with le-sions that he could hardly open his eyes. His family had come to be with him.

"He was taking a very, very long time to die," remembers Jones. "After a while, it starta wearing on people's nerves." As she helped him bathe one morning, he turned to heiped han bathe one morning, he turbed to her and said, "I feel like I'm lettling every-body down." They shared a largh about it. Then he grabbed her arm. "But you know, Diane, I have a commitment to life,"

"I thought, my God, even in the state that

be's in, death is not an escape to him." She remembered her own periods of depression and moments of suicidal thinking. "It was

and moments of suicidal thinking. "It was very stamming to me," she says. It got me in touch with how shallow my commitment to Effe was, and how precarious. "Ward 5A is a very intense work expe-rience," says Jones. "People who end up there are drawn to that quality. My own mortality—it made me deal with it. I may not have the answers, but the questions are right in my face." right in my face."

right in my lace." Jones voluntered to work on the ward after working with AIDS patients on other floors at San Francisco General, before the AIDS ward was established. "As a lesbian, I was spalled by the homophobia," she recalls. "I heard a surgeon say, 'I have to go stick a tube down the throat of a faggot in room 15.'"

She reported people who made homopho-bic remarks to their supervisors. "I don't think it was maliciousness on their part, she recalls. For most people it was ignorance. You had to give people information to overcome their fears."

Jones' 9-year-old daughter Annie has grown op with her mother working on the ward. She has visited and become friendly with AIDS patients. "She talks about death a lot more freely," says Jones. "She has shocked adults by talking about her death and my death."

7 10 member a lot of different patients," says Marcy Fraser, a nurse who worked on the ward from the fall of 1984 to March 1987. "I remember one guy stopping at the outpatient clinic on his way to work. He had his briefcase and his suit on. He thought he might have the flu. The outpatient clinic diagnosed him with AIDS-related pneumonia and admitted him. He was just crying and crying and crying.

"I cried a lot on that job," she says. "I thought, gee, I'm not the one who's supposed to be crying here, but patients liked [knowing] that people could abore what they're (refing. They were so dependent on us," she says. "They felt we belonged to them."

The ward was—and remains—no ordi-nary place to work. At one end is "The Eliz-abeth Taylor Room," a lounge that got its name after the actress visited the ward and taiked to atif and patients. One patient do-pated a poster of "Cat on a Hot Tin Roof." featuring Taylor in a black slip; an auto-graphed photo of the actress, wearing a striking pecklace of nearly and diamonds, is also on the wall. also on the wall. The gay community and their friends have adopted the ward. Volunteers spend time visiting patients. A donation keeps the freezer stocked with pints of ice cream. Rits Rockett, a community activist who had a friend die on the ward, caters a brunch for

patients, staff and families every other Sunday. Sharon McNight, a popular singer in gny enbaret chibs in San Franciscu, comes on occasion, waving her boa and singing Patsy Cline songs. On one visit, two of McNight's friends served as cocktail wait-

ers, distributing glasses of champagne and freshly squeezed orange juice. "I loved that job," recalls Fraser. "I used to jump out of bed. I couldn't will to go to work in the morning. I feel like we took really good care of people

For a time, she says, she ran into patients nd their families everywhere she went on her days off. "I remember eating dinner out with a friend, and a guy came up to our table and just started sobbing and sobbing. He was the brother of one of our patients who had died."

When her first female patients appeared on the ward, she says it became more difficult to distance herself from the disease. "I really got used to men getting sick." she says. "When I started having more women patients, I realized it was spreading. The undoing for me was George

Fraser. George Jalbert was a close friend of hers from nursing school. He worked on the ward from the day it opened, and he sug gested that she come to work there, but Jal-bert had AIDS-related complea, and he began to feel worse.

"He started getting really tired and taking a nap on his lunch break," says Fraser. "He began losing weight and started looking terrible." On the Sunday of Labor Day weekend in 1986, Jalbert called Fraser and asked her to take him to the hospital.

He wanted to go to San Francisco Gen eral, she recalls, but she balked. "I said, "Come on, George." It would have been too much, she says. She took him to another hospital where he was diagnosed with cry-ptococcal meningitis and AIDS. He never came back to work. "It was the first time it was one of us." she remembers.

On her days off, Fraser spent tir Jalbert, but the stress of dealing with AIUS on her job and in her personal file became too difficult. "I was so choked up with losses and with grieving and dying," she says, "I needed to step back from the bedside. The pain was getting to be too much."

She left the ward and now works as an attendant care aupervisor at Visiting Nurses and Hospice of San Francisco. But after two and a half years away from the bedside, she has started to miss it. She says she will go back anon to direct patient care. "It's what I am, so AIDS nurse."

Jone Meredith Adoms is a freelance writer in San Francisco

a Abd worth reach service a

Levy and Morrison honored by AmFAR on World AIDS Day Newsford (2/17/94-1/15/95



Levy

On December 1, World AIDS Day, Jay A. Levy and Clifford L. Morrison were honored by the American Foundation for AIDS Research (AmFAR) for their work fighting AIDS and the challenges facing people with HIV. The awards were presented during a luncheon at the United Nations in New York City.

Levy, professor, medicine and research associate, Cancer Research Institute, received AmFAR's Award of Distinction for his innovative and consistent contributions to AIDS research. One of the first researchers to isolate HIV, he recently presented research that paves the way for developing and testing HIV vaccines using animals. His research exploring the question of natural immunity revealed that long-term survivors of HIV in-

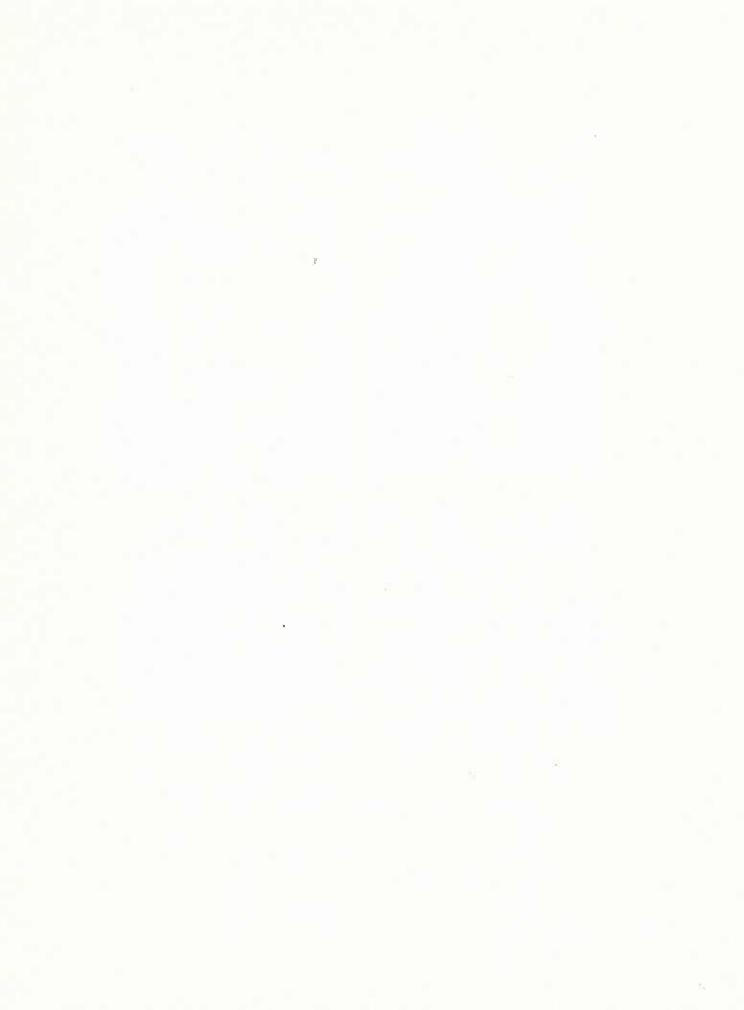


Morrison

fection possess CD8 cells that block HIV replication, which may lead to entirely new treatments for HIV.

1 Contraction

Morrison, director of clinical services, Epidemiology and Prevention Interventions Center, SFGH, received AmFAR's Award of Courage for his dedicated and compassionate caregiving to individuals with HIV/AIDS. He established the first dedicated inpatient unit for people with AIDS, which became a model for care that has been replicated nationwide. His energetic advocacy of AIDS-related issues has influenced health care policy at the national, state and local levels. Morrison also works as a volunteer caregiver in his off hours.



Famed AIDS ward fading out

As new drugs save more lives, S.F.'s Unit 5A is transformed

By Ulysses Torassa Examiner Mediçal WRITER

Since the beginning of the AIDS crisis, San Francisco General Hospital has been singled out as the best in the nation, a model of what AIDS care could, and should, be.



A key piece of that has been Ward 5A, where AIDS patients were treated to donated baked goods, unlimited Double Rainbow ice cream, teddy bears, campy volunteer visits and unusually compassionate care from nurses who signed up to be part of the experimental unit. TV crews and journalists from around the world traipsed through regularly to feature the ward, where the staff bonded with patients living through the sometimes excruciating final weeks or months of their [See AIDS, A-20]



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Nurse Tim Otto, who began as a volunteer on Ward 5A, takes the blood pressure of Timothy Caldwell.

Famed AIDS ward phasing out

lives.

But like everything else connected to the AIDS epidemic, things on Ward 5A have changed, an Examiner/KTVU Channel 2 report shows. Much of it has been gradual over the last several years as the patient profile changed, the number of volunteers dwindled, and new drugs slashed the death rate.

The last straw may have come last month, as a funding crisis at the hospital combined with a spike in overall admissions forced the ward to grow to 34 beds. It once was limited to 20. And fewer than half of the beds are now occupied by AIDS patients.

"There is no AIDS ward anymore," said Ann Steinlauf, who was among 13 registered nurses who volunteered to be on the inpatient unit when it opened in July 1983 and remains on staff in 5A. "It marks the end of an era. It's quite sad," said Tim Otto, who began as a volunteer on the ward nine years ago and was so impressed he went on to become an R.N. and returned to be a staff nurse on the ward. "Something extraordinary that has been going on here is dying. Maybe no one cares. Maybe it's time to let it die."

Administrators aren't ready to say what will happen to the inpatient AIDS ward, which has been an AIDS/oncology ward for at least the past four years anyway. A severe bed shortage that hit hospitals all over The City last month prompted them to add 10 beds eight of them in a matter of hours — filled with patients of all kinds.

"When the nurses walked into the unit, they were told, 'You are getting eight extra patients today and cope with it,' "Otto said. "A lot of nurses just started crying."

Hospital Administrator Gene O'Connell praised the staff for rising to the occasion, and said there are no plans to do away with the AIDS ward. The staff on 5A was told the situation would be re-evaluated in March. Still, O'Connell noted that new drugs thankfully have cut the need for inpatient AIDS care. Meanwhile, the hospital'a outpatient clinic for AIDS has grown from 300 visits per month at the beginning of the epidemic to 2,500 visits today.

day. "I have to think of all patients. I can't just keep a ward one certain way when the rest of the hospital has to respond," O'Connell said.

Once, savvy AIDS patients clamored to get onto 5A, which was

> "Something extraordinary that has been going on here is dying. Maybe no one cares. Maybe it's time to let it die."

- Nurse Tim Otto

consistently filled. But drug therapies and better hospice services kept people at home, and the ward began taking cancer patients to remain full. Now there is a good chance an AIDS or HIV-positive patient will end up in an ordinary ward rather than 5A, according to Steve Keith, a nurse on the ward since it opened.

And for years, 5A had mostly private beds and a staffing ratio better than other wards, which didn't endear them to the rest of the hospital.

"We really weren't well-liked," Steinlauf said.

According to Keith, "They want us to be just as poorly staffed as every other ward in the hospital."

But forces beyond the hospital's control have also diminished the ward's special status.

Thirty people — mostly gay men — once were regular volunteers, giving massages, running errands, holding hands and offering support. Today four people come by to help. Six months ago, Rita Rocket, whose crew has been serving every-other-week brunches to the ward for 15 years, cut back to once a month, citing a 90 percent drop in donations and volunteer burnout.

The Godfather's Service Fund collected robes, slippers and toiletries for AIDS patients and distributed them cheerfully room-toroom. Now the group drops off the items at the front desk, and nurses pass them out, partly to cut down

on awkward feelings aroused in non-AIDS patients. The staff has had problems, too, with patients wearing their nice new robes to the smoking lounge and then trading them for a pack of cigarettes.

Last week, the staff voted to cut out the all-you-can-eat Double Rainbow ice cream, partly because it had become abused by patients and partly because it was earmarked for people with AIDS, but the majority in the ward did not have AIDS.

The staff, once entirely made up of registered nurses who had volunteered and been trained for the ward, is now a mix of R.N.s and licensed vocational nurses, who require less schooling. Only about half the current staff specifically requested to be on Ward 5A. The rest were assigned.

and the other clinics over there as real models to look at," Durazzo said. "People have traveled from all over the world to see how it's organized and set up. But clearly there's a shift now, given the access' to new drugs and so forth.

"I think there is very much of a mind-set that is slowly creeping into people's perceptions of the epidemic that it's really over, that the focus and energy and resources that were needed five years ago are no longer needed at that level," he said.

The new drugs have slashed AIDS deaths in The City from a high of 1,817 in 1992 to just 279 last year. And while most people with HIV in San Francisco are still gay men, they are also increasingly likely to be racial minorities, home-

less or drug abusers.

Durazzo's organization sees the effects in everything from diminished support from foundations to difficulty recruiting and keeping volunteers for the hot line. Other AIDS groups like Shanti and Open Hand also are having trouble finding people willing to care for the new type of AIDS patient — marginalized, often homeless or drug abusers, often minorities.

"It's not volunteering time up in the Castro anymore," Durazzo said. "It's volunteering your time in the Tenderloin and people aren't

AIDS RA

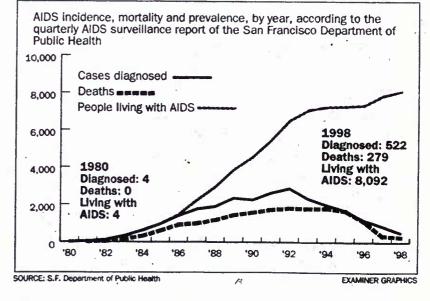
stepping forward so readily to do that."

Past news accounts, books about AIDS and the staff describe Ward 5A as an innovative model of care that involved patients, the community, and the nursing staff. In the beginning, it was full of gay white men in the prime of their lives who often brought a sense of humor and fun as well as an overwhelming feeling of tragedy to the ward.

"We had some incredible patients back then — I had a composer, we had artists and writers," Steinlauf recalled.

Recently she paged through one of the ward's many scrapbooks, pointing out a flyer for a patient's art shows. There were photos of herself and other staff members celebrating with patients, and obituaries and hand-written memories of the thousands of who have passed through the ward in the past 15 years.

In her book about AIDS care at San Francisco General, "As Real As It Gets," author Carol Pogash described how the ward was started by nurse Cliff Morrison after he saw the poor care AIDS patients were getting scattered about the hospital. In the early days of the epidemic, people were scared of catching the disease and many on



"In the early days, the common refrain was. It could just have well been one of us in that bed.' " - Nurse Steve Keith

the staff were reluctant to treat AIDS patients, or even to clean their rooms.

Patients helped design the ward, which from the outset ignored many ordinary hospital rules, like limited visiting hours. People were encouraged to bring items from home. Morrison once crawled into a bed with a patient and held him after the patient asked him to.

"We had so much time to spend with each individual patient," Keith recalled of those early days. "People had millions of questions, and details of their lives they wanted to share with us. There'd be gay men who had been disowned by their family years ago and who had burned a lot of their bridges. They'd be sobbing in their bed about their predicament and there would be these gay men nurses

holding them while they sobbed."

lover who had decided to have a commitment ceremony at the ward. A room was cleared and decorated. A cake was made. A nurse and a Shanti counselor served as the attendants.

Since there were no medical treatments for AIDS at the outset, nurses became experts at handling the diarrhea, pain and nausea that plagued so many. Now they are skilled at the complex drug regimens that HIV-positive patients must follow to stave off the disease.

But that expertise is useless with patients who are in the hospital for gall bladder operations, heart failure or other illnesses who end up on 5A.

"When I'm given a patients with colitis, truth is I'm just trying to make sure I don't do anything wrong," Otto said.

The staff is quick to say that the patients need and deserve the compassionate care as much as ever. But they don't attract the same level of volunteers, donations and support of the hospital.

"In the early days, the common refrain was, 'It could just have well been one of us in that bed.'" Keith said. "Half the staff were gay men and the patients here were white professionals like us."

Now, he said, "it's Tenderloin Keith recalled a patient and his junkies and homeless people, people not really invested in their health care. They don't follow up, they continue to shoot (drugs). They're less appreciative of the staff and volunteers. Volunteers have told me, 'I don't feel appreciated here anymore and I don't like dealing with these patients.""

> Still, nurses on the staff say morale is higher on Ward 5A than on some other wards, and patient care remains good, even though shortstaffing has created havoc at times.

> But those who signed up to work on the ward because of its special nature feel a sense of loss.

"I feel like it's one of those unrecognized civic treasures," Otto said. "It's nice to have a new Civic Center with its gold dome and so on, but another wonderful thing that San Francisco did was pioneer this approach to AIDS care that served as a model for the nation. It's provided excellent care to people at the very bottom rungs of society and that is just passing away silently and unnoticed."

See this story Sunday on KTVU Channel 2's "10 O'Clock News."



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