

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

U·M·I

University Microfilms International
A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313/761-4700 800/521-0600

Order Number 9304705

**Transformation and transcendence: Caring for HIV-infected
patients in New York City**

McGarrahan, Peggy Gatheral, Ph.D.

City University of New York, 1992

Copyright ©1992 by McGarrahan, Peggy Gatheral. All rights reserved.

U·M·I

**300 N. Zeeb Rd.
Ann Arbor, MI 48106**

A

TRANSFORMATION AND TRANSCENDENCE

CARING FOR HIV INFECTED PATIENTS

IN

NEW YORK CITY

by

PEGGY McGARRAHAN

A dissertation submitted to the Graduate Faculty in Anthropology in
partial fulfillment of the requirements for the degree of Doctor of
Philosophy, The City University of New York

1992

c 1992

PEGGY McGARRAHAN

All Rights Reserved

This manuscript has been read and accepted for the
Graduate Faculty in Anthropology in satisfaction of
the dissertation requirement for the degree of
Doctor of Philosophy.

8/19/92
Date

Shirley Lindenbaum
Chair of Examining Committee

8/17/92
Date

Dell Jones
Executive Officer

Professor Shirley Lindenbaum
Professor Dell Jones
Professor Ida Susser

Supervisory Committee

THE CITY UNIVERSITY OF NEW YORK

Abstract

TRANSFORMATION AND TRANSCENDENCE

CARING FOR HIV INFECTED PATIENTS IN NEW YORK CITY

by

Peggy McGarrahan

Adviser: Professor Shirley Lindenbaum

In this study I am primarily concerned with understanding nurses' experience of caring for HIV infected patients. It is an experience in which they face issues of human life that American society would like to forget: issues surrounding death and dying, sexuality and deviance, fear and abandonment. Through helping patients deal with these questions, the nurses in this study find that they must face and understand these issues too. Thus, in enabling their patients to come to terms with HIV disease, the nurses in this study come to terms with it themselves.

As their patients experience change and development, these nurses, because they facilitate and participate in their patients' transformations, are transformed also. They and their patients become more reconciled to the human condition, to the existential fact that all who are born must die. Through reconciliation, they paradoxically affirm the value of living for each individual, even though each must die. This affirmation enables the nurse and patient to relate to each other on a plane divorced from social definitions and ascriptions. Both nurse and patient transcend social boundaries. They establish a relationship based on the belief that all people have at least one thing in common, their membership in the

human race.

The viewpoint underlying this research is that a profession can constitute a way of 'being in the world', and so can become, for its practitioners, a special universe. Committed professionals embody a particular set of principles and practices. For the nurses in this study, who are committed professionals, their profession is not just "a technical task but ... a cultural frame that defines a great part of their lives" (Geertz 1983:155). This study seeks to illuminate the cultural frame of the nurses in this study and to understand how these nurses create and maintain that frame.

ACKNOWLEDGEMENTS

The research on which this study is based would not have been possible without the generosity of the nurses I interviewed. They each took time from demanding jobs and full lives to talk with me. I will always be in their debt. I can only hope that what they read here faithfully reflects what they conveyed to me.

The New York Chapter of the Association of Nurses in AIDS Care [ANAC] welcomed me as an affiliate member from the very beginning and the help of the members of the chapter was critical to getting started and to completing this study. I wish I could fully express my appreciation of what they did for me.

Many others have helped me understand what it is I present here. My adviser, Professor Shirley Lindenbaum, encouraged and supported me from the first. Her keen insight, combined with good cheer, helped me bring order and structure to the project. My committee members, Professors Delmos Jones and Ida Susser, were generous in their comments and suggestions. The manuscript is the better for them. Dr. Carol Germain of the University of Pennsylvania School of Nursing, my outside reader, was a meticulous commentator and critic. Her careful reading of the manuscript was invaluable. So was that of Dr. Ellen Baer of the University of Pennsylvania School of Nursing, who was the first to see and help me see what it was I was describing.

Financial support was provided by the Robert F. Wagner, Sr. Institute of Urban Public Policy through a dissertation fellowship research grant. I am grateful for their assistance and their interest

in my work.

To all who contributed to the genesis and progress of this project I extend my thanks and gratitude. I am sorry the project is finished. The experience of trying to understand what I discovered has been exhilarating and rewarding. I hope that what I have written does justice to it.

CONTENTS

I	Introduction	1
II	Methodology	13
III	The Sample	21
IV	HIV Disease and Other Epidemics	26
V	HIV Disease in New York City	51
VI	The Environment of HIV Disease in New York City	74
VII	Meeting HIV Disease	90
VIII	Choosing HIV Care	98
IX	The Challenges of HIV Care	116
X	Providing Care	149
XI	Dilemmas of Care	169
XII	The Rewards of Care	190
XIII	Self-Knowledge	203
XIV	Consciousness and Time	215
XV	Nursing as a Moral Undertaking	224
XVI	Death and Transcendence	240
XVII	Contemplative Cognition	257
XVIII	The Appeal of HIV Care	272
XIX	Images of Care	287
	Appendix A	294
	Appendix B	296
	References	308

TABLES

Table 1	115
"What prompted you to become involved in HIV care?"	
Table 2	
"What are the challenges of what you do?"	147
Table 3	
"What keeps you going?"	168
Table 4	
"Do you meet any ethical issues in your work?"	189
Table 5	
"What are the satisfactions?"	202
Table 6	
"When you think of being a nurse, does any particular image come to mind?"	239

I Introduction

Human Immunodeficiency Virus disease [HIV] is culturally unsettling because it challenges the principles and practice upon which Western medicine has relied so successfully for a generation. HIV disease cannot be cured, at a time when many of scourges of former times have been virtually eliminated. And it affects the young, at a time when most illness seems to be the province of the middle aged and/or old.

For most of this century, the human life span has grown longer and longer, beyond even the biblical three score and ten. Now, with HIV disease, early death is becoming commonplace again. Since the advent of antibiotics, infectious disease in the United States seemed inconsequential. With HIV disease, infectious disease is making a comeback. HIV disease is thus psychically unnerving because it undermines expectations, for both the patient and the caregiver.

Most HIV infected patients are young or in the prime of life. They are infectious and they are almost sure to die. Many of them are engaged in sexual and/or drug cultures which may be foreign to their caretakers. They may have no material or familial resources. They present many practical management problems.

The clinical parameters of the disease are not yet known. Medical success in treating the opportunistic infections which affect HIV infected patients has paradoxically enabled the disease to develop new manifestations. The result is that yesterday's knowledge is often inadequate for today.

HIV disease has been called "an astonishing rebuke to a society and its healthcare professions accustomed to the idea that the fight

against disease is being progressively won" (Murray 1987). Yet for the nurses in this study, it is also an opportunity to demonstrate the power of nursing as a healing art and the relevance of a social vision that combines humane caring with technical and scientific expertise.

The crisis of HIV disease affects all aspects of the healthcare system, but its most direct impact is felt by nurses because they are charged with the personal, 'hands on' care of the sick. In carrying out this responsibility, nurses are continually making decisions, for their patients, for themselves, for the institutions they work for, and for their profession. Conflicts and contradictions occur because of differences between nurses and their patients, between institutions and the nurses they employ, between nurses and other healthcare providers, and between and among nurses themselves.

Professional training, experience and personal preferences may or may not work together. Religion, gender, ethnicity, and class may or may not influence how nurses resolve the demands made upon them. In addition, the media presentation of HIV infection as both a disease and a social phenomenon may or may not increase the difficulty of caring for these patients.

In order to deal with HIV disease nurses must be able to tolerate ambiguity, uncertainty, and difference. They must be receptive to new ideas, new therapies, new kinds of patient-caregiver relationships. They must be open to their patients.

Openness is possible when nurses view the people they care for as patients first, and social beings second. In the concept of the 'patient', the 'other' is categorized as a human being in distress and in need of care. The care is given because the person is a human being

and human beings of whatever race, ethnicity, gender or sexual preference should be treated well. Thus, this concept of 'patient' represents a moral commitment, a commitment encapsulated in these nurses' images of care. Using this category of 'patient' enables the nurses in this study to overcome the fear, repugnance, avoidance and hostility which normally arise in socially uncertain encounters (Perin 1988).

In meeting the challenge of HIV disease, the nurses in this study articulate and practice a philosophy of care which is based on a recognition of shared humanity between patient and caregiver. This philosophy enables these nurses to respond positively to patients who do not fit the American cultural ideal and to solve the dilemmas which arise from a new and devastating disease. It is a philosophy which reaches back to the beginnings of professional nursing but which also incorporates recent social developments, particularly the change in locus of decision-making (Cassell 1991). It thus looks forward as well as back. Models of medical decision-making have until recently assumed that the physician, as the professional with the most advanced training, should have the final say (Melosh 1982; Starr 1982). For the nurses in this study, the patient should be the one to decide; the professional's role is to make sure the patient has all the information needed to make that decision (Allan 1988).

For the nurses in this study, nursing can be defined "as that service to the individual that helps him [sic] to attain or maintain a healthy state of mind or body; or, where a return to health is not possible, the relief of pain and discomfort" (Henderson 1939 quoted by Baer 1991). In a recent video, Henderson said: "As a nurse, I try

to do for [patients] what they would do for themselves if they had the strength, the will, and the knowledge that a nurse has. And I try to do it in such a way that I don't make them dependent on me" (New York: NLN Video, 1990 quoted by Baer 1991).

Nursing, in this context, means acting with and for the patient in whatever manner will enhance the patient's health. It is a very comprehensive concept with few outer limits. How much is done for the patient will depend on the patient's condition, but at the core of this kind of nursing lies this connection with a patient, an individual human being. Nursing can thus be distinguished from medicine, which is primarily the diagnosis and treatment of disease. Nurses "are involved with activities that contribute to diagnosing disease and they also activate many of the therapeutic mechanisms that treat diseases" (Baer 1991:3), but their focus is on the effect of disease on the individual patient.

Nursing is also distinguishable from ancillary healthcare, such as that provided by physical therapists and social workers, by its overall responsibility.

Nurses decide which care is needed by which patients, set up the plan of care, assign the appropriate level of personnel to give that care, and oversee it from beginning to end. This work takes knowledge, judgement, and a whole array of skills that are based as much in the social and behavioral sciences as they are in the biological and medical sciences. (Baer 1991:3)

Nurses who embrace this conception of nursing must be competent in a number of domains of knowledge so as to assess correctly what is happening to the patient and to act accordingly.

Such nurses become interpreters to whom patients and other personnel turn. In fact, as Baer goes on to say,

nursing bridges the gap between people and science; nurses explain medicine to patients and patients to medical practitioners. (1991:3)

This kind of nursing is interactive and creative. It is a kind of nursing which the nurses in this study practice. For these nurses and for their patients, it can become an endeavor in which they support each other. How this endeavor is undertaken and how it progresses, along with what it means for these particular nurses and for their patients, is the subject of this study.

I begin with a comparison of HIV disease and other epidemic disease of the 20th century. I then describe the appearance of HIV disease in New York City and note the sequence of challenges which this disease has presented to practitioners and institutions committed to the care of the sick. I consider how the philosophy of nursing these nurses profess enables them to turn towards rather than away from those afflicted. I describe what nurses gain from their involvement with their patients. I then look at the cognitive and emotional skills which are required and reflect on what it is that HIV care makes possible, for nurses and for nursing.

What these nurses gain from caring for HIV infected patients is greater knowledge of other people, of disease, and of themselves. They gain personally and professionally from intimate association with their patients, illustrating Merleau-Ponty's dictum that "intellectual elaboration of our experience of the world is indissolubly linked to the elaboration of our interpersonal relations"

(quoted in Malson 1972:56).

Furthermore, these nurses' contact with their patients expands their capacity for an integrated, non-linear cognition which meshes rationality with emotion (Agan 1988; Sarter 1988). Their thinking about their patients combines scientific knowledge with knowledge about the patient's emotional, physical and social state, so that the conclusions arrived at are not the result of a mechanistic matching of symptoms to solutions, but reflect also the nurse's individual response to the person of the patient. Thus, in the act of caring, they create, however briefly, an encounter which permits the humanity of both patient and caregiver to flourish. It is in such encounters that the appeal of this kind of nursing lies.

It is my contention that the philosophy of nursing which the nurses in this study espouse, similar to the philosophies of care which support other service professions, is a moral statement about human social relations. HIV care gives these nurses an opportunity to turn this moral statement into reality. The opportunity exists because HIV disease is a particular kind of illness, because HIV disease presents a particular kind of patient, because the control hospitals and physicians normally exert is sometimes relaxed in HIV care, and because the attitudes of openness and accessibility which these nurses exhibit find strong echoes in the current political discourse in New York City concerning the rights and entitlements of individuals.

In this study I am primarily concerned with understanding the experience for the nurse of caring for HIV infected patients. It is an experience which requires nurses to face issues of human life that

American society would like to forget: issues surrounding death and dying, sexuality and deviance, fear and abandonment. Through helping patients deal with these questions, the nurses in this study find that their own understanding is enlarged, and so what they do for their patients they do also for themselves. As Michael Jackson says of anthropological fieldwork, "the discoveries we make about others are valued only to the extent that we recognize them as reflections on ourselves" (1988:205). In this process of mutual engagement with their patients, these nurses become clearer to themselves.

Thus, for these nurses, the experience of nursing HIV infected patients enriches their lives personally as well as professionally. Their patients become their mirrors, just as they reflect their patients' images back to them. In this "recurrent reflection" (Reik 1949), nurses become acquainted with themselves through acquaintance with their patients. As Reik said of psychoanalysis, "By taking it [the patient's experience] into ourselves, we learn something too of what is going on, or has gone on, in ourselves" (1949: 419). The same holds true for nursing.

The relationship that these nurses establish with their patients is a reciprocal one. They enable their patients to come to terms with HIV disease; in so doing, they come to terms with it themselves. As their patients experience change and development, these nurses also experience transformation. They and their patients become more reconciled to the human condition, to the existential fact that all who are born must die. Through reconciliation, they paradoxically affirm the value of living for each individual, even though each must die.

This affirmation enables the nurse and patient to relate to each other on a plane divorced from social definitions and ascriptions. This is transcendence.

Reconciliation and affirmation are not restricted to the nursing of HIV infected patients, but HIV infected patients, in their disease and in themselves, are more likely than other patients to trigger existential questioning. They compel their caregivers to think about human destiny and the social order.

The unremitting fatality rate of HIV infected patients brings questions of mortality to the fore. In addition, the stigmatization of many HIV infected patients, and the extreme poverty many endure, can be shocking to nurses, who are by and large, middle class and mainstream. Caring for so many who are so ill and so poor cannot help but bring to mind questions about the fairness and justice of the social order. The nurses in this study respond to these questions by transcending the social order and establishing a relationship based on the belief that all people have at least one thing in common, their membership in the human race.

It is my contention that the techniques nurses use to discover who their patients are and what is happening to them are similar to those which anthropology relies on. The strategies and behaviors which nurses use to cope with difference underlie much ethnographic research. Nurses are participants as well as observers of the experience of illness. They stay with their patients; they are "there" for them. Their 'field' is the hospital or clinic or home. Their patients are 'natives'. It is from them that nurses discover what being infected with HIV is like. For the nurses in this study, HIV

infected patients are the 'other' whose experience can illuminate their own and critical to that understanding is spending time with their patients. Time enables these nurses to know their patients well. Time also enables these nurses to reflect on their own reactions to the patient and to HIV disease. As Cassell comments about anthropological methods:

... central to the method [of fieldwork] is the researcher's spending long periods of unstructured time with those studied. In fieldwork, the observer is her own measuring instrument; it is the researcher's reactions to the researched that provide data. Rather than seeking to measure or predict, the primary aim of ethnography is to understand. [*Italics in the original*] It is open-ended: the researcher goes into "the field" to examine the situation rather than clearly defining and delimiting all the relevant "variables" ahead of time. The method is frequently more time-consuming than a purely quantitative study, since the researcher cannot specify in advance the exact nature of the phenomena that will be examined, analyzed, and compared. The investigator does not enter the field with planned, and possibly arbitrary measures and criteria; instead, the research is guided by the unfolding events in the field. As a result, fieldwork is extremely flexible. It can discover the unexpected and adapt to unforeseen and rapidly changing circumstances. It is prodigal of time and of intellectual and psychic energy, however, since the research route has not been precisely mapped in advance. (Cassell 1992:

227-228)

In order to understand their patients, nurses must be attuned to their patients' point of view, must integrate that point of view into their own understanding, and then they must serve as the translator for both the patient and the outside world. In so doing, a high degree of intellectual and emotional engagement is required.

This engagement I call contemplative cognition. It is a kind of cognition which blends physical, mental, and emotional information. The nurse remains alert, attentive, and responsive as she uses all her skills to understand the patient and to devise an appropriate plan of care. In this activity she experiences wholeness, because she is able to combine domains which are usually separate. HIV care thus offers these nurses a special opportunity to experience integration of body, mind, and heart.

The particular kinds of empathy and cognition so important to nursing and ethnographic research are not, of course, unique to these professions, but anthropology and nursing do something more than use these skills. They institutionalize them in the tradition of fieldwork and in the discourse of 'care'. They are the practitioner's primary tools. It is through the exercise of these skills that the nurse and the anthropologist achieve their goals, the one to understand some facet of social life, the other to understand illness.

The viewpoint underlying this research is that a profession can constitute a way of 'being in the world', and so can become, for its practitioners, a special universe. Committed professionals embody a particular set of principles and practices. For these nurses, who are committed professionals, their profession is not just "a technical task

but ... a cultural frame that defines a great part of their lives" (Geertz 1983:155). This study seeks to illuminate the cultural frame of the nurses in this group and to understand how the nurses create that frame. It is an attempt to "gain access to one another's vocational lives" (Geertz 1983:160), and in so doing, to render less puzzling the mystery of what other people do and why they do it.

For nursing as a profession, the debate over the care of HIV infected patients has reactivated discussions about the spirit, the goals, and the techniques of nursing. Humane treatment of HIV infected patients, like humane treatment for other conditions and for human beings in general, has to be fought for. Nursing thus has to be continually reconstituted and its meaning renewed. Crises such as HIV disease can be an opportunity for redefinition and recommitment. As Dr. Rieux, the hero of The Plague, says at the very end:

None the less, he knew that the tale he had to tell could not be one of a final victory. It could be only the record of what had had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, while unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers. (Camus 1948:278)

My goal has been to present these nurses' experience as much as possible from their own point of view. I have sought to render what they do and the reasons they do it "from the inside" (Sanday 1983:19). It is their story, told in their own words. And it is from the direct evidence of what they said that the reader can evaluate

how accurately I have interpreted them.

Above all I have tried to present a full and fair description of what is involved in HIV care, and particularly how the understanding of what is involved is the result of a slow accretion of actions, reflection, feeling and thought. By focusing on the phenomenon itself, I have tried to avoid simplistic explanations of why these nurses have chosen to do this work and what they get out of it. Many domains operate at once in HIV care. It is this richness and complexity which I hope I have conveyed.

II Methodology

This study draws on several kinds of information. First, and most important, is the personal experience of nurses in HIV care. I gathered this data in individual interviews with fifty nurses. Second is my own observation as a volunteer in two New York City hospitals and as a member of a nurses' specialty association (Association of Nurses in AIDS Care [ANAC]). ANAC promotes the dissemination of knowledge about nursing care for HIV infected patients and serves as a support group for nurses working in HIV care. Third is the validation for the information garnered from interviews which came through a survey of the members of the ANAC Greater New York Chapter. Fourth is the confirmation from informal conversations with a small group of nurses who met on a regular basis to discuss issues and concerns in their work. Finally I use library materials as historical background to nursing in the United States in general and nursing during similar outbreaks of disease in the past.

The interviews of nurses active in HIV care were conducted between November 1989 and September 1991. The participants were volunteers, both to my study and to the care of HIV infected patients. For eight, the care for HIV infected patients was a part of a general nursing position. The others, forty two out of fifty total, chose to specialize in HIV care, although they were all in a position to seek out jobs which would not involve much contact with HIV infected patients. This research was conducted at a time when nurses were in very short supply in New York City; these nurses could have changed jobs if they wished. Instead, they actively sought out a position caring for HIV infected patients.

From initial introductions to nurses doing HIV care I gained contact with others, many of them introducing me to their friends and colleagues. Each nurse was asked a series of open-ended questions which led to far-reaching discussions of each individual's experience. Each nurse was then contacted nine to twelve months after the first interview for a shorter, follow-up appointment. Twenty three of the fifty agreed to a second interview. Six of the nurses I interviewed read and commented on a draft of this manuscript.

The original and follow-up interviews varied in length from one hour to three. They took place in a variety of settings and at different times of the day. Some nurses could only meet during working hours, others at lunchtime, some after work. We met in offices and coffeeshops, homes and hospitals. The setting and the time naturally influenced the course of the interviews, particularly those conducted in work settings where interruptions and distractions could occur, but in each one I encountered an individual who found in the interview an opportunity to share and reflect on the experience of nursing HIV patients.

The interview format followed a regular pattern; I had a list of open-ended questions which I covered in each session [Appendix A], but I was alert to ideas and topics not on the guide which my interviewees were interested in discussing as well. My list of questions served as a guide to exploration; I began with them but I was always ready to follow the interviewee's lead. I tape-recorded and then transcribed each interview and reviewed the transcripts carefully, coding for common themes and patterns. I used what I

learned in the transcripts to add and/or expand questions and perspectives from the interview questionnaire in succeeding interviews (Patton 1990). I was thus continually refining the process during the research period. At the end of the process, the responses of the nurses interviewed provided the data which I incorporated into the survey I mailed to the members of the New York City Chapter of ANAC.

Using interviews as the primary source of data was particularly appropriate to the focus of this research and to the actual situation of the nurses in this study. The day-to-day experience of nurses at work is task oriented, but the meaning of nursing is not revealed in an analysis or description of the tasks they perform; the meaning lies in the integration of the task with the nurse's consciousness. This is not apparent in simple observation. It comes clear through reflection, when the nurse examines her own reactions to what she is doing, away from the patient, the bedside, and the care setting. This is why interviews were a good vehicle for exploring what the experience of HIV care is for this group of nurses. They needed to reflect on and analyze their experience in order to articulate what HIV care means to them. Interviews gave them that opportunity.

Because the interviews took place over a long period of time, relying on this technique also gave me the opportunity to reflect on what I was hearing. As the study began, I first sought to describe the experience of nursing HIV patients without prejudgments or expectations. I then isolated what I saw as particular to the experience and focused on how the nurses themselves understood their experience. Finally I looked for the meanings which were not

immediately apparent to the nurses themselves nor to me, but which were inherent in the experience.

In this I followed the phenomenological method described by Spiegelberg, in which the goal is to focus on the "things themselves" (1976:656). I tried to approximate a "first seeing" in all its complexity, before analysis and interpretation began. I paid particular attention to the processes through which the understanding of nursing HIV infected patients was achieved, especially that first encounter with the patient, and then succeeding encounters which crystalized the experience in the nurses' consciousness. My aim was not to dissect the experience into parts and rank them, but to try and relate them to each other and to adjacent social and cultural phenomena. Through this approach I hoped to preserve and honor the multifariousness of the experience of nursing HIV infected patients. I sought complexity rather than simplicity; I tried not to diminish the experience. And I used as my guide, Spiegelberg's reminder that:

The genuine will to know calls for a spirit of generosity rather than that of economy, for reverence rather than subjugation, for the lens rather than the hammer. (1976:657)

This method is a "determined effort to look at the phenomena [being studied] and to remain faithful to them while thinking about them" (Spiegelberg 1976:700). It is attentive to the variety of modes in which phenomena appear and the greater or lesser adequacy with which we perceive them. In this study I am particularly concerned with the stages by which HIV disease established itself in the consciousness of the nurses in this study and in my own. What is in

our consciousness does not appear all at once; it gradually takes form. I have tried to convey this development over time through the organization and presentation of the material. The first meeting with the HIV infected patient is followed by successive encounters which add something to what was known before. The experience becomes increasingly complex over time. And only with time does the meaning of the experience become apparent.

This study is thus a qualitative one. I use interpretive techniques which "seek to describe, decode, translate and otherwise come to terms with the meaning, not the frequency, of certain phenomena in the social world" (Van Maanen 1983:9). I am more concerned with ambiguity and particularity than with definitions and replication. I have, therefore, tried to avoid the constraints of "analytic labels, abstract hypotheses, and preformulated research strategies" (Van Maanen 1983:10).

Interviews are the core of this study but they are not the sole source of data. I joined the Greater New York Chapter of the Association of Nurses in AIDS Care (ANAC) when it was in the process of formation in November 1989, and I continue to be an active member. ANAC is similar to many other nurses' groups formed around a specialty practice. There are associations of nurses in cancer care, intensive care, pediatrics etc. These associations provide their members with contacts and up-to-date information, and they frequently serve as advocates to the public for the patients their members care for.

ANAC, as a national organization, seeks to serve as a clearinghouse for clinical knowledge about HIV disease. In addition,

it operates as a kind of support group for nurses directly involved in patient care. It also speaks up publicly on questions relating to the care of HIV patients. For example, it has taken formal positions on the 'duty of nurses to care' and the testing of health workers. These positions have been presented to the Center for Disease Control when guidelines and regulations are under consideration. The association organizes an annual conference on the subject of nursing care for HIV infected patients.

The New York City chapter of ANAC meets once a month for discussion of issues and concerns related to HIV disease, and it sponsors lectures on topics of interest to nurses taking care of HIV patients. The lectures usually focus on clinical topics, such as new drugs, the new CDC diagnosis criteria, or the identification and management of dementia in HIV infected patients. The organization fosters social and professional contacts among nurses interested in improving the care of HIV infected patients. The association was helpful in providing me with on-going contact with a group of nurses who report to each other about what is happening with the disease and with patients in the greater New York area. Thirty three of the nurses I interviewed came from ANAC. I could not have carried on this research without the support and encouragement of the members of the New York Chapter of ANAC.

When the first round of interviews was finished, I sent out a questionnaire incorporating what I had discovered in the interviews to all the names on the mailing list of the Chapter. Of the one hundred and seventy nurses who received the questionnaire, fifty six responded. These fifty six did not include members of ANAC I

interviewed. Six questionnaires were returned undelivered. The completed questionnaires confirm the validity of the interviews. Where appropriate, survey results are incorporated into the body of the narrative, but they are also presented in Appendix B, and comparisons of interview and survey responses follow Chapters VIII, IX, X, XI, XII and XV.

In addition, I met with another small group of nurses, numbering from two to five, on a more informal basis at regular intervals from April 1990 to September 1991. At these meetings they talked about what was happening on their units or in their clinics and how they were dealing with the challenges and difficulties of HIV care. This smaller group facilitated the expression of opinions and feelings which might have been difficult to elicit in a more impersonal setting.

I also served as a volunteer at two New York City hospitals from April to December 1990. One hospital was part of New York City's municipal hospital system; the other was a not-for-profit hospital in Manhattan. At the municipal hospital I was first a member of a team conducting a survey of HIV infected patients. We administered a detailed questionnaire concerning each patient's personal and medical history with the aim of collecting enough data to develop a profile of the hospital's HIV infected clientele. As a member of the survey team I saw patients in almost every unit of the hospital and I saw firsthand the kinds of patients HIV brings to the hospital and the kinds of care they require.

When the HIV survey ended, I joined the group working out of the Patient Relations' Office who surveyed hospital patients generally

about the care they were receiving. This position enabled me to learn about patients' care in general and because I covered every unit I was able to observe the interactions of nurses and patients within the hospital setting.

At the not-for-profit hospital I was a member of the Patient Relations' staff assigned to welcome new patients, orient them to the hospital, help them solve whatever problems they had, and make sure they understood the Patient's Bill of Rights. Both of these tours of duty enabled me to observe the pace and organization of hospital nursing, the relations between patients and caregivers, and the special requirements of patients with HIV disease.

Finally, I spent several weeks in library research on the history of nursing in the United States with special attention to nursing during times of outbreaks of infectious disease.

I thus draw on a number of different kinds of information in this study. I have personal knowledge drawn from direct observation in hospital settings. I have narratives from nurses directly involved in HIV care and I have survey material that provides quantitative support for the interview findings. I also incorporate scholarly studies of other medical crises as well as contemporary analysis of HIV disease in the United States and New York City in particular.

III The Sample

The group of nurses I interviewed for this study, fifty in all, is not by any means representative of all or most working nurses in New York City. This is a small sample of experienced, highly educated, dedicated nurses who have chosen to do HIV care. There are 52,844 nurses in New York City currently registered with the New York State Division of Professional Licensing. Westchester and Nassau Counties have 27,621 registered nurses. In contrast, the total sample of this study numbers fifty, of whom forty four are women and six are men. Forty three are white, five black and two Hispanic. None of the male nurses is black or Hispanic. Two nurses are in their early twenties, twenty six are between the ages of thirty and forty, nineteen fall between forty and fifty, and three are over sixty.

All are registered nurses. Twenty eight hold baccalaureate degrees. Of these twenty eight, five are nurse practitioners, six have master's degrees and three have Ph.Ds. In addition, a number of them are pursuing a further degree as well as working. At the time of the interviews, two were enrolled in baccalaureate nursing programs, six were pursuing master's degrees, two were studying to be nurse practitioners, and two were in doctoral programs.

Six have been working less than five years, three less than ten but more than five, twenty five less than twenty but more than ten, eleven less than thirty but more than twenty, and five more than thirty years. Forty seven of them have been working in their present positions for less than five years. They chose to be more involved in HIV care. Forty two out of the fifty spend 100% of their time in HIV care.

The majority of this sample are therefore experienced nurses who know their profession and know what they want from it. Before becoming involved in HIV care, thirty nine worked in hospitals, sixteen doing general nursing, mostly on medical surgical units, two on psych units, ten others in high-tech intensive care units, coronary and critical care, and one in an emergency room. One served as midwife in high risk maternity, two others were in oncology, five were nurses in hospital clinics for ambulatory patients. Two others were in homecare services, hospital based. Of those not in hospital positions, two were teachers. Three were already working in homecare agencies. Two had just completed a stint overseas, one in the Caribbean, the other in Cambodian refugee camps. Three were public health nurses. One was a nurse to a doctor in private practice whose patients were primarily gay men. Most of these nurses became aware of HIV disease as part of their job, and then chose to become more involved in caring for HIV infected patients. For this group of nurses, HIV care is a conscious choice.

Thirty three of the nurses are members of ANAC, the Association of Nurses in AIDS Care, and it was through ANAC that I recruited them for this study. The others were referred to me by the nurses I interviewed.

Thirty six of the nurses in the group work in Manhattan, seven in Brooklyn, two in Queens, and one in the Bronx. Two work in Westchester and two others in New Jersey and Long Island.

Thirty five work in a hospital setting: twenty six in voluntary hospitals and nine in public or municipal hospitals. This division is somewhat misleading, however, because ten of those currently

working in voluntary hospitals gained their HIV experience in the municipal system. As the voluntary hospitals set up HIV units and clinics, they recruited staff from the municipal hospitals. Nine work only in outpatient clinics, sixteen in inpatient units, and ten in both. Eighteen are staff nurses, but six of these nurses have additional responsibilities for case management, inservice education, patient counseling and research. Eight are mainly supervisors, coordinating care. Three are administrators, but one administrator is also inservice educator and another has direct supervisory responsibilities. Six are research nurses for clinical trials of new drugs and treatments.

Nine work in homecare, three as staff nurses, two as administrators, and four as case managers and supervisors of field nurses. Eight work for non-profit agencies; one for a for-profit organization specializing in homecare for HIV infected patients.

One is a staff nurse for a residential facility and one works for a research organization, coordinating HIV/AIDS programs at city hospitals. Four teach nursing, three at the graduate level and one at the undergraduate.

They came to nursing from diverse directions. Nursing in the United States has always been a female occupation, and the profession has traditionally attracted ambitious young women from working or lower middle class families for whom a professional R.N. license was a step up in status. Until recently, nursing was one of the few professions which welcomed women. The others were elementary and secondary teaching and social work.

Thus, for many of this group, their career choices when they

were young were to be a nurse or a social worker or a teacher. They chose nursing. For some nursing was an interest they manifested from an early age. They bandaged their dolls and treated them for ailments; they read Cherry Ames and biographies of famous nurses such as Florence Nightingale and Clara Barton. For most it was also a route to a steady, professional job which promised financial security. For others it was a choice made without a great deal of thought. But all, at the time I spoke with them, felt it had been a good choice, no matter how arrived at.

Most of them received their initial training in hospital or diploma schools and then went on to get a further degree. Some of them, however, did not feel the need to get another degree, and it is important to note that the R.N. is a professional license.

The sample is thus composed of highly educated, motivated nurses, many of whom hold advanced degrees. It is disproportionately white and disproportionately male, since 97% of R.N.s in the United States are women. Almost all of them bring to the care of HIV infected patients years of experience in other nursing specialties. They are mature, professionally and personally.

That which truly sets them apart, however, is not their experience or their educational achievements. What they share, above all, is an unusual interest in HIV disease; most of these nurses sought out the positions they hold. This sets them apart from many of their colleagues who are either not interested in HIV care or who actively avoid it. They themselves note that they differ from many of their colleagues in their interest and concern for HIV infected individuals. It is this special characteristic which makes what they

have to say so important. They want to be successful in the care of HIV infected patients, and they are in a position to consider from the perspective of their own practice, past and present, what HIV care means, how it compares to other kinds of nursing, and what it asks of nurses.

This study therefore is an interpretation of these particular nurses' experience. It focuses on what the meaning of the experience is for these nurses; that meaning is arrived at through the nurses' self-reflection and analysis. They, as well as I, were interested in finding out why they chose this work, what it offered as compared to nursing other diseases, and what it might reveal about nursing's underlying mission.

There was no question I asked which they had not already asked themselves. This made them collaborators as well as contributors, as the significance of what they do has become clearer to them and to me in the course of this study. Six of those interviewed agreed to read and comment on drafts of the study. Their comments were invaluable.

IV HIV Disease and Other Epidemics

Commentators have sometimes used an exaggerated rhetoric in comparing HIV disease to the Black Death and other scourges in the past, so it is important to be careful in drawing comparisons between HIV infection and other epidemics. Each epidemic has its own pattern of morbidity and mortality, and each epidemic occurs within a particular society, at a particular time. The social aspects of disease must be taken into account as well as the medical. However, comparing HIV disease to the two episodes of virulent and uncontrollable disease in recent American history, the influenza of 1918-1919 and the polio outbreaks from 1916 to 1955, is instructive because it helps to identify what HIV has in common with those diseases and what sets HIV disease apart. A further comparison with the history of syphilis in this country illuminates the similarities between HIV disease and venereal disease. These comparisons in turn clarify how the nursing of HIV infected patients compares to nursing in other epidemics.

The flu of 1918, popularly called the Spanish flu, was first reported in the United States in troop encampments in Massachusetts. Influenza was not a new disease; there were six major epidemics in the 19th century alone, the last in 1889-90 when 40% of the world's population is thought to have been infected, but there were certain characteristics of the 1918 flu which were unusual.

The first unusual aspect was its pattern of infection. Flu has always been a danger to the very young and the very old, neither of whom have optimally operating immune systems. But the 1918 flu

attacked indiscriminately, and its mortality was highest among the group most likely to be best able to repel the infection, adults between the ages of 21 and 40. Mortality in the United States was highest among those aged 21 to 29.

One theory advanced for the mortality among this group is that in the young adult the immune response is at its most vigorous and so in these patients the lungs became highly inflamed in response to the infection. As a result, what was described as a "spring tide of fluids" overwhelms the lungs and the patients die of respiratory failure. In patients over forty the body's ability to respond quickly and thoroughly to an infection declines. This improves patients' ability to survive generalized infections, while their ability to survive localized infections from wounds or broken bones declines. Thus young people were more at risk because their bodies made a more spirited attack on the invading virus. This flu was indeed followed by a higher incidence than usual of pneumonia, which in large part accounted for the high mortality. Patients had high fevers; they sometimes bled from the nose, and their lungs, after death, were found to be filled with a watery, bloody fluid. (Crosby 1989)

The flu came in three major waves, the spring and fall of 1918, and the early months of 1919. In all, worldwide, it is estimated that 20 to 22 million people died in the space of a year. One fifth of the global population is thought to have been infected. These figures are actually considered to be both low and inaccurate because reporting procedures were primitive in 1918-1919, and some flu deaths are thought to have been attributed to other causes. In the United States 500,000 +/- people died.

The disease attacked both rich and poor in the United States, but some groups had higher mortality than others. Italian Americans were very hard hit. One doctor complained that he could not get them to isolate patients. Native Americans had a mortality rate four times that found in the cities, approximately 9% of those infected died. Black Americans had lower mortality rates than other groups. (Crosby 1989)

The disease killed quickly and randomly. Some families were spared altogether; in others, one member only might not become sick. Facilities to care for the sick were overwhelmed. Those struggling to care for others often became ill themselves and when parents were laid low, the household suffered. As one public health nurse in San Francisco described the scene she found at a home in the Sunset district: "There was no food in the house. The windows were all tightly closed and the house was more of a pigsty than a home" (Crosby 1989: 96).

There were no known treatments and no cure. Care consisted of what nurses characterize as 'comfort care'. This means that patients are kept clean and warm. They are fed and watched. Aspirin was a new drug at that time, so there was little beyond traditional measures to combat the severe fevers which frequently resulted in delirium. As a result, people turned to homespun remedies. They hung cotton bags with lumps of camphor around their necks. They drank violet leaf tea and chewed garlic buds. They gargled with water and carbolic. They soaked handkerchiefs with eucalyptus oil and covered their mouths and noses when they went outside. Chest poultices of bran, lard, camphor, chloroform,

turpentine and onions were applied. Laxatives were recommended. Exercise was promoted. Officials recommended wearing masks and handwashing was required in stores and restaurants. (Crosby 1989) In Canada, native Indian lore was exploited. Wild ginger was used in teas or mashed into a wad and kept in one's cheek. Bark from the cottonwood tree, yarrow and wild cranberry bark were used for infusions. Skunk musk was applied to the skin. (Pettigrew 1983)

The effects of the epidemic were far-reaching. Many of those who survived were left with heart trouble and respiratory weaknesses which made it impossible for them to pick up their lives as before. Many children were orphaned. The elderly lost adult children. Businesses suffered and some failed. Insurance companies were hard hit with claims. There was considerable social and economic dislocation.

The European war of 1914-1918, which was winding down as the flu epidemic struck, provided a perfect locus for the flu virus to enter the human population. Troop encampments, troop ships, the trenches in France, all offered good opportunities for an infection to spread. Troop movements back and forth across the Atlantic as the armistice approached and as fighting men were brought home enabled the germ to penetrate the civilian population. In addition, the ability of the virus to mutate as it passed through different groups meant that people could be struck by a succession of infective agents. Their immunity to one would not protect them from the next.

The need for people to care for the large numbers taken ill was great but the war had drained civilian facilities of personnel. There were 8500+ nurses serving in Europe when the call for nurses to

tend flu patients came. The Red Cross and the Federal Public Health Service called for volunteers. Many retired nurses responded; many who were married with children left their families to care for the sick. Temporary hospitals were constructed and many lay people stepped forward to help. The Red Cross held classes in nursing and appealed to women in general. One appeal in San Francisco ran: "It is the duty of every well woman in the city who can possibly get away from her other duties to volunteer for this emergency". Another said: "Women of San Francisco, We Beseech Your Help" (Crosby 1989:82;97).

The public did come forward. Neighbors took care of each other. People with cars became ambulance drivers. Fire departments provided transportation. Families whose breadwinner was stricken found that friends did their chores if they lived in the country and/or stepped in to keep households running. Most people behaved with courage, fortitude and kindness; traditions of sharing and neighborliness were strengthened. As Alfred Crosby says: "Americans by the hundreds of thousands did lend each other a helping hand, despite the lack of institutional structures to enable them to do so and despite deep schisms in their society" (1989:115). He goes on to quote Professor Francis Peabody of Harvard University who said that the public's response to the crisis was "extraordinary evidence of the capacity of a free people to organize themselves for an emergency" (1989:116). As the Boston Evening Transcript of 26 October 1918 commented: "They have not only made the city of Boston a safer place to live in, but also a place in which one may be proud to live" (Crosby 1989:116).

In addition to providing care for the many afflicted, the public health and medical community mounted an effort to identify the cause of the influenza. Between 1918 and 1930, 4,000 books and articles were published on the flu. The search for the infective agent was undertaken in the United States, Europe, and Japan.

The search consisted of four steps: first, to identify the infective agent, second, to isolate it, third, to grow it, and fourth, to develop a vaccine to counter it. The techniques for producing vaccines were known and several flu vaccines were produced, but none was effective. The real difficulty lay in finding the germ. The equipment available at the time could filter out bacteria but viruses slipped through. There was no way to grow viruses in culture; animals were needed and finding a suitable animal proved difficult. In addition, the conviction that only human beings contracted influenza meant that the similarities between human influenza in 1918 and an outbreak in that same year of respiratory disease among horses in Europe and the United States was ignored.

It is possible that greater attention to this phenomena might have speeded the discovery of the flu virus because it was through the similarities between human influenza and canine distemper that the first effective flu vaccine was found. English researchers were successful in isolating a virus causing flu when an outbreak of flu in England in 1933 inspired investigators to use the techniques developed while studying canine distemper to infect ferrets with the human virus. Eventually human blood from those who had recovered from the flu was found to contain antibodies against the infective agent recovered from ferrets also suffering from influenza,

proving that the ferrets and human victims were infected with the same germ.

With this achievement it became possible to develop a vaccine against the human flu virus. Eventually the public health systems of the industrialized countries became able to monitor the appearance of new strains of influenza as they appeared from time to time worldwide and to produce quickly a vaccine specifically designed for each variation. It thus became unlikely that, while such public health measures were maintained, a repetition of the 1918 pandemic would occur.

In the United States, meanwhile, the work of Richard Shope in discovering the cause of swine flu was another step forward in understanding how viruses can attack their hosts. Shope was intrigued by reports in 1918 of a new disease among pigs in the Midwest. This new disease caused high fevers, coughs, muscle soreness, drippy noses and eyes, and it seemed as though it could be passed from pig to farmer and vice versa.

What Shope eventually demonstrated was that swine flu was caused by the synergistic action of a flu virus and Pfeiffer's bacillus. Only the two together caused a serious disease and their combined action needed to be set off by cold, wet weather. The virus which Shope isolated from the pigs in the American Midwest was almost certainly a descendent of the 1918 virus because Londoners who survived the pandemic showed high levels of antibodies to the swine virus, whereas those born after the pandemic did not.

Pfeiffer's bacillus was long thought to be the cause of the human flu itself because it was commonly found in samples taken

from patients, but all sorts of other germs were also present: staphylococcus, streptococcus and pneumonococcus. In addition, these germs frequently accompany less dangerous infections such as colds and tonsillitis.

Shope's hypothesis was that the flu virus was latently present in the pig population, for days, weeks, perhaps months or years. To become active and to actively cause disease, it had to be triggered by both the presence of Pfeiffer's bacillus and cold, damp weather. The virus thus lurks within the organism until the conditions are right.

Shope believed that this is what happened with the 1918 human flu virus. He thought that the early, mild wave of flu in the spring of 1918 seeded the population, so that when another agent appeared and spread, the more deadly disease developed. This remains a theory; it is not proven, but it is intriguing because so many deaths in the pandemic were the result of secondary infection, particularly pneumonia and strep.

The other scourge of the 20th century in the United States, poliomyelitis, like influenza, was not a new disease. It was first reported in Europe in 1789 as a mysterious disease of fever with residual paralysis, a disease which showed a marked preference for children. In the 20th century, there was a Swedish outbreak in 1905 and the disease attracted a good deal of medical attention. Between 1909 and 1913, Flexner, in the United States, published a series of papers on the disease. By that time it was known to be a viral infection.

The first serious outbreak in the United States occurred in 1916 when 27,000 became ill, of which 6,000 died. After that there

were periodic episodes in cities and states around the country: 1930, Middletown, CT.; 1931, New York City; 1932, New Jersey and Pennsylvania, Los Angeles; 1935, Boston, Annapolis; 1936, Alabama, Chicago, Tulsa; 1949, New York City; At no time was the whole country affected. Even at its height, it was a relatively rare disease. The numbers bear this out. In the worst year, 1952, 60,000 cases were reported, of which only 3,000 died. Overall mortality was low; most recovered, and only a very small percentage were permanently crippled.

It is true, however, that after World War II, the incidence of polio in the United States showed a marked upsurge. Some think that the polio virus was brought back by soldiers returning from southern Europe and North Africa where the disease was endemic. In 1940, 10,000 cases were reported. In 1945 to 1949, 20,000 cases were reported each year. From 1949 to 1952, the number of cases continued to climb until the peak was recorded in 1952 when there was one polio case recorded for every 3,000 in population. Thereafter it fell off slightly, until the development of the vaccine in 1955 effectively eliminated it. (Smith 1990)

Polio, as an epidemic disease attacking children, is thought to be an unanticipated consequence of public health measures undertaken in the late 19th century. The provision of closed sewers immeasurably improved the health of urban dwellers, but it meant that infants were no longer routinely exposed to the polio virus at a time of life when infection does not produce paralysis. Polio became a threat when it changed from an endemic to an epidemic disease. Vulnerable populations, particularly in cities, became infected when

the virus found an opportunity to spread.

It is still not known exactly how the polio virus is communicated from person to person. It is thought now that fecal contamination was the mechanism of transmission, but during polio scares, any contact between strangers was discouraged because many believed that the disease could be transmitted through the air. Thus any large congregation of people was avoided. Parents forbade their children the pleasures of swimming in community pools; movie theaters were suspect. In addition, energetic campaigns against bugs and dirt were initiated. Various prevention measures, similar to those used in the flu epidemic, were recommended. Vitamin C and peanut oil were both thought to have protective power. (Smith 1990)

Polio's onset was insidious. It frequently started as a feeling of general malaise. Some thought that they were coming down with a summer cold. They might feel poorly for several days and then suddenly collapse. They would trip or stumble and find that their bodies did not respond, or they would wake up one morning unable to move.

As with the flu, there were no successful treatments and no cure. In 1939 only 300 hospitals in the country would accept polio victims because there was nothing they could do for them. People had to make do at home, and there were few facilities for rehabilitation for those who survived in a crippled state. Some doctors made it worse by encasing patient's limbs in plaster casts so they would not become contorted. But this contributed to wasting and atrophy. Damp, hot packs were sometimes applied to paralyzed joints in the hopes of maintaining flexibility. For those whose lungs

were paralyzed, the iron lung, which enabled patients to breathe, became a temporary haven from which they eventually had to be weaned. Until the advent of Sister Kenny from Australia, a nurse with innovative and successful notions of rehabilitation, the typical polio victim with residual paralysis was kept at home, and people managed as best they could.

Those who were hospitalized were often admitted to special orthopedic or contagious disease hospitals where nurses had little experience with polio. Again the nursing community was asked for volunteers and nurses responded, many coming out of retirement or abandoning vacation plans and/or family responsibilities when polio made an appearance in their community. (Downes 1989)

As with influenza, the medical community organized an effort to look for a cure for polio, and here polio had an advantage in the person of Franklin Delano Roosevelt, a polio victim himself. He was determined not to let his paralysis impede his political career, and the image he presented to the world, of an energetic, forceful man who just happened to be crippled, was helpful in reorienting the public's view of polio victims. He was instrumental in starting the drive to establish research programs aimed at polio, and eventually the support of the whole nation was enlisted in the campaign for funds called the March of Dimes. The March of Dimes, with its posters of crippled but cheery children, was a brilliant undertaking. It garnered support from every segment of society. (Smith 1990)

The search for the vaccine against polio began in 1916 when the first serious outbreak occurred in the United States, but it was only after World War II that large amounts of money were directed

at research. Most of the money raised during the Thirties and early Forties was used for the care and rehabilitation of polio patients. The switch to research was the result of a confluence of science, money and academic expansion.

Charitable foundations started making grants to universities, enabling departments to expand and improve their buildings and equipment; the National Foundation for Infantile Paralysis, the parent of the March of Dimes, gave grants for academic research, and new techniques made new kinds of research possible. For example, Dr. John Enders in 1948 discovered how to grow the polio virus in test tubes, a remarkable advance which freed research from reliance on animal hosts. Polio only attacks humans, monkeys, and chimps. Humans as experimental subjects, even if they volunteer, pose all sorts of problems. Monkeys and chimps are expensive. With test tube cultures, researchers could grow and study large quantities of the virus.

Dr. Jonas Salk, based at the University of Pittsburgh, led the research which produced a dead virus vaccine in 1955, and Dr. Albert Sabin, in 1959, was the leader of the group who successfully produced a live vaccine which could be taken orally. The Salk vaccine was safer than the Sabin, but it required several injections, and it only protected people from paralytic polio. The Sabin vaccine, although one dose in four million carries a lethal virus, protects people from any kind of infection with the polio viruses. The Sabin vaccine eventually became the vaccine of choice because it is simpler to administer than the Salk vaccine.

This rapid review of the influenza and polio epidemics reveals

a complex of similarities and differences when they are compared to HIV disease. All three developed at a time when the world's populations were in unusual movement. War, in the case of influenza and polio, gave the germ the chance to penetrate new and vulnerable populations. Jet travel and immigration among so many areas of the globe (Africa, the Carribean, Europe, the Americas and Asia) has performed the same function for HIV disease.

All three are viral diseases and viruses are protean and mutable, but the degree to which these viruses are mutable differs. The polio virus has only three stable forms. The flu virus changes frequently. The HIV virus has two known forms and may have others. Thus once the polio vaccine was developed, the job was done. The polio viruses do not suddenly change their make-up. The flu viruses do, so vaccines have to be constantly up-dated, and patients have to be innoculated with the current vaccine to prevent infection.

Because the HIV virus apparently works indirectly on the human organism, a direct analogue with the polio and flu viruses is impossible. In addition, the relation between viral infection and accompanying bacteria is still unclear. Dr. Luc Montagnier, the discoverer of the first HIV virus and director of the Pasteur Institute in France, recently suggested that the virus might be triggered by mycobacteria, a suggestion which recalls Shope's theory of the 1918 influenza.

There are also researchers who challenge the theory that HIV disease is caused by the virus. Dr. Peter Duesberg of Berkeley, an expert on retroviruses, contends that the variety of manifestations of the disease argues against a viral cause. "No other known microbes

show such clinical and epidemiological biases" (Heimhoff 1990:6). Dr. Alan Cantwell focuses on mycobacteria as the infective agent in both cancer and HIV disease, noting that both diseases present the same opportunistic infections.

The search for a vaccine against the HIV virus continues, one effort is led by Dr. Salk, but so far the techniques which were successful against polio and influenza have not been successful with HIV.

The influenza virus is transmitted through respiration, making it very contagious. It is not clear how polio moves through a population, but HIV disease seems to be relatively difficult to transmit. Bodily fluids, such as blood and semen, contain large quantities of the virus; contact with these substances and other fluids, such as mucous membrane secretions and breast milk, in which the donor's fluids mingle with another's, seems to be the manner in which this virus moves from one host to another.

From what is known so far, only those who come in contact with intimate bodily fluids are at risk. This has made it difficult to construct an all encompassing set of symbols in the public consciousness, symbols which would generate widespread concern and support. In the influenza epidemic, people didn't need symbols; everyone knew someone who was ill. Polio had Franklin Delano Roosevelt and the gallant children of the March of Dimes posters. HIV disease has Ryan White, but it struggles with other, less sympathetic images of drug addition, deviance, and sexual promiscuity. Kimberly Bergalis, the young woman infected with HIV by her dentist, represents an outcome which the public fears but the

medical establishment persists in downplaying. She is not a symbol around which different groups can coalesce. The recent announcement by Magic Johnson, the basketball star, may provide the disease with an effective spokesman, but in his public comments he seems to be distancing himself from homosexuals and IVDUs. He may not be willing to stand in for all those infected.

Everyone was at risk for influenza during the pandemic of 1918. Only an absolute quarantine of contact with other people, like the one achieved in American Samoa, could screen a group from infection (Crosby 1989). Polio, on the other hand, at least in the United States, was never a nationwide occurrence. Each year a number of cities would be struck but never all at once. Its impact was uneven.

So seems HIV disease. So far, gay men and IV drug users compose the majority of cases. Women who are the sexual partners of IV drug users are the next largest group. The children of HIV infected women are a small but growing category. Some have contracted HIV disease through blood transfusions or treatments for haemophilia. But there are some cases which do not fit into the major risk categories at all, so there may be other methods of transmission which are not yet known.

The fact that people can carry the HIV virus for a long time without becoming ill is one of the major distinctions between this disease and either influenza or polio. With influenza and polio, illness followed infection rapidly. With HIV infection, people can have the virus without knowing it and can pass it along to others. This makes HIV infection difficult to track and to contain. The

estimates of how many Americans are infected are statistical extrapolations, and the material on which the extrapolations are made are likely to be inaccurate. Given the stigma attached to the disease, many cases are probably not reported. Also HIV infected people die of diseases which do not fit the CDC criteria for HIV disease, and, therefore, their deaths are not included in official figures.

For these reasons and others, perhaps a closer parallel to HIV disease than either influenza or polio can be found in the history of syphilis in this country. It is also a systemic, blood disease and one which has a long latency. As a venereal disease, it was considered shameful, and many doctors colluded with their patients in keeping the diagnosis hidden, until it became apparent in the late 19th and early 20th century, that women and children were the ultimate victims of men's infection. Concern for those innocently affected spurred public discussion of syphilis, and there were many of the same concerns as with HIV disease about casual contact with those infected. People worried, for example, whether it could be passed through public drinking fountains. Public toilets were also suspect. Much as prostitutes are now, women in general were seen as reservoirs of infection, particularly during the 1920s, when sexual mores relaxed. Insurance companies refused to give policies to syphilitics and some companies dismissed syphilitic workers. (Brandt 1985)

The infective agent of syphilis is a spirochete, *Treponema pallidum*, which

gains entry by burrowing into the skin tissue of a sex partner.

After entry, it reproduces at the site of entrance and, within a few hours, has grown into a colony of millions of spirochetes that begin to spread by way of blood and lymph circulation throughout the body. (Jones 1974:57)

The disease has several stages. The first indication is usually a primary lesion or chancre which may not even be noticed. In women, of course, chancres are less frequently observable than in men. The primary chancres disappear spontaneously, but the disease is still present in the blood. In four weeks to six months, secondary signs appear. These may be rashes, sore throat, mild fever or headache. New lesions on the mouth or sexual organs may develop. Hair and eyelashes may fall out, the eyes become inflamed, jaundice, pain in the joints, and in very severe cases, meningitis, convulsions, deafness, partial paralysis, and sometimes coma.

The symptoms of secondary syphilis persist for a variable period of time and then disappear spontaneously. The continuing presence of the disease can only be detected by blood test. This is a stage of "hidden syphilis". If untreated, people with latent syphilis can be expected to exhibit late manifestations which will kill or incapacitate them. The most common are cardiovascular infections, specifically of the aorta, paralysis and dementia due to the destruction of brain tissue, degeneration of the optic nerve and the loss of muscular coordination. (Jones 1974:64)

Like HIV disease, syphilis exhibits a multitude of signs and symptoms. It was called "the great imitator" because there are "at least forty skin diseases that secondary syphilis may resemble, twenty three diseases that syphilitic mouth lesions may resemble,

and at least sixteen diseases that resemble primary genital lesions" (Jones 1974:56). Like HIV disease, syphilis has been an underlying cause of many deaths, but one that has often not been recognized.

Like HIV disease, syphilis has had a higher incidence among the poor, and particularly among black Americans, than among better off, Caucasian groups. The possibility of infection was associated with class, race and gender. City and state health departments in the 1930s, for example, sometimes required domestics and food handlers to be tested for syphilis. There were many of the same judgments made about promiscuity among the poor as there are now about sex in crack houses. As Brandt comments, "Since the early 20th century, physicians, particularly in the South, had suggested that blacks were unusually prone to venereal disease, a 'syphilis-soaked race'" (1985:157).

The attempt to discover just how prevalent syphilis was led to some overestimation of how many were infected. At one time one in ten Americans was thought to be infected. As Brandt says, the numbers "reflect the uncertain nature of diagnostics during the period [early 20th century]" (1985:13). Like HIV disease, other infections were probably diagnosed as syphilis, and possibly what was syphilis was diagnosed as other diseases. When the definitive Wasserman blood test became available and the National Venereal Disease Control Act was signed in 1938, providing federal money for testing and treatment, the actual rate of infection, as measured by premarital tests, was found to be much lower than expected. In New York City, in the first year that the requirement took effect, only 1.34 tested positive for syphilis. (Brandt 1985:149) Thus, until the blood

test became commonplace and required, the real incidence of syphilis, like the incidence of HIV disease, was unknown.

The fact that penicillin is effective against syphilis was discovered by Dr. John Mahoney at a Public Health Service Hospital in Manhattan in 1943 (Brown 1970). From that time on, particularly after penicillin treatment became commonplace, syphilis cases declined, and the fear and stigma attached to the disease disappeared. In the 1970s and thereafter, for a variety of reasons including the sexual revolution, the gay rights movement, and the decline of funding for public health programs, syphilis and other venereal diseases, particularly gonorrhea, have reemerged as serious public health problems. HIV infection compounds the difficulty of containing the spread of these infections.

HIV disease and syphilis, in the absence of definitive blood tests, masquerade as other diseases, and each patient, therefore, presents an idiosyncratic history. The symptoms of HIV disease and syphilis are not uniform, unlike influenza and polio, whose manifestations remain the same whether the patient is young or old, male or female, rich or poor, American, African, or Asian. This is not true of HIV infection. Americans very commonly contract PCP, but Africans do not. The most common expression of HIV disease in Africa is a wasting syndrome. In the United States, men and women differ in the opportunistic infections they contract. Children are particularly prone to a form of pneumonia called lymphocytic interstitial pneumonia or LIP for short. Gay men are more apt to have Kaposi's sarcoma than other groups are. IV drug users frequently present with TB. HIV disease comes in any number of

combinations of infections; it does not have a single set of symptoms. (Harawi and O'Hara 1989)

Patients with influenza were quickly ill and either quickly recovered or quickly died. The acute stage of polio was also quite short. There might be permanent effects, but the malaise and illness phase were not long. With HIV infection, however, now that quite effective treatments are available, patients with HIV disease can live for many years. In addition, many of those infected with the virus do not manifest symptoms of illness. This is also true of syphilis. An initial period of acute illness can be followed by a long period of latency. Like HIV disease, the final stage of syphilis is frequently accompanied by dementia.

These diseases also exhibit different patterns of morbidity and mortality. Influenza was marked by very high morbidity and a relatively low mortality. Polio had both low morbidity and low mortality. Once penicillin became widely used, the morbidity rate of late and late latent syphilis dropped precipitously from 153 per 100,000 in 1941 to 9.7 in 1979 (Brandt 1985: Appendix), and the mortality rate declined from 15 per 100,000 in 1939 to 1.3 in 1965 (Brown 1970:132). Therefore, until the recent upsurge in STDs (Sexually Transmitted Diseases) in general, syphilis could be characterized as a disease of both low morbidity and low mortality.

HIV disease also has a relatively low morbidity; the latest CDC estimate (1992) is that 182,000 out of a population of 250 million have full blown HIV disease, while a million more may be infected with the virus. Mortality for HIV disease, in contrast, is expected to be 100% unless a cure is found. Young adults form the largest cohort

of deaths from HIV disease as they did for influenza, but the growing number of pediatric cases may make HIV infection a disease which kills both young children and young adults. It thus carries with it the potential for a population implosion. In this it also resembles syphilis, which can be transmitted from mother to child, sometimes killing the fetus unborn or mentally or physically deforming the full term child (Jones 1974).

Influenza, polio and HIV disease each found the medical system in disarray, without the knowledge and facilities to care for the ill. A concerted effort was mounted in each case, both to provide the care needed and to find a cure. The consequences of that effort differed, however, with varying effects on the overall medical system. The influenza epidemic gave the CDC an opportunity to show its usefulness; the polio epidemic encouraged universities, foundations and the federal government to cooperate in research. It also spurred the development of rehabilitation techniques. So far, the major effect of HIV disease on the medical system has been to loosen the controls over the use and dissemination of experimental drugs. New legitimate procedures, although cumbersome, now make it possible for patients to get new drugs before final approval by the FDA.

HIV disease has to some extent pitted the public against the medical profession and other health professionals. Because HIV is often framed as a civil rights issue rather than a medical one, public health has become a contested terrain. The contest even pits members of the health professions against one another. Recent Federal attempts to regulate the procedures HIV infected doctors can

perform and to require doctors and other health professionals to be tested have been vigorously resisted by the New York State Health Department. Who is to be protected, who determines the risk, and who assumes the risk are still to be decided.

All four diseases elicited fear and terror and avoidance. One nurse during the influenza pandemic reported that people drew away from her in the railroad car as she traveled to her post (Pettigrew 1983). In New York City, the outbreak of polio in 1916 was attributed to the "poor, densely populated waterfront area of Brooklyn called 'Pigtown' in the jargon of the day" (Ludmerer 1989:11). Pigtown was inhabited by Italian immigrants, and authorities imposed a harsh quarantine, although there was never any epidemiological evidence to support the charge that the Italians had introduced polio from their homeland.

Nurses themselves were sometimes prone to hysterical responses. During the polio years, in several hospitals nurses came down with a mysterious paralysis which disappeared as swiftly as it arrived (Smith 1990). The media efforts in the 1930s to alert the public to the problem of syphilis stressed the dangers of the disease and thus created an atmosphere of fear (Brandt 1985). Some of the same phenomena can be observed in current education efforts on HIV disease. Any sexual contact at all is sometimes portrayed as potentially fatal.

The care given to patients was similar for both the flu and polio: bed rest, treatments to reduce fever, liquids, good food and cleanliness. Each patient's body waged its fight against infection without drugs or chemicals. The nursing time devoted to each

patient was quite short, and the outcome was either successful or not. The patient recovered or died.

Syphilis presented a somewhat different challenge. Until the discovery that penicillin cures syphilis, patients were subjected to a variety of treatments, some more horrific than the disease itself. At one time, they were literally baked in a box, the theory being that the germ could not survive high temperatures. (A similar therapy was briefly tried for HIV disease: the patient's blood was withdrawn, heated, and then returned.) Arsenic and mercury, substances poisonous in themselves, were used to combat the disease. The most successful compound developed from arsenic, Salvarsan or arsphenamine, had to be injected intravenously, and many physicians were not familiar with intravenous procedures. Syphilis was, however, the first disease to be attacked on a grand scale with a chemical drug.

Treatment for HIV disease also relies on chemical therapies. Powerful drugs keep patients alive; their use is highly complex. Patients need complicated technical and sophisticated intervention if they are in the midst of an acute illness, and they need continual monitoring between episodes of acute illness. Patients linger on, recovering from bouts of infection, but never completely cured. The disease does not kill quickly. But it does kill eventually and it is because it does kill, paradoxically, that it provides an opening for nursing to affect the process and philosophy of medical care today.

It is HIV disease's high mortality combined with the chronicity of the disease which may facilitate the spread of nursing's philosophy and attitudes, even when the crisis of HIV infection is

past, because it is in attitudes towards death and dying that nursing differs quite radically from medicine, and it is in these attitudes that nursing values are most visible. In crisis situations, such as the influenza and polio outbreaks, the value of nursing is apparent, and nurses are eulogized for their selfless response to the sick. But once the crisis is over, nursing's philosophy and attitudes fade into the background again.

This may not happen with HIV disease because patients are never cured, they are treated while they die, and this can take a long time. How this can be done humanely is what nurses committed to HIV care demonstrate and what they teach other health professionals as well as members of the public, their patient's families and friends. Thus nursing's way of doing things and way of thinking about things is disseminated beyond the bedside, the unit, the clinic, or the hospital.

In addition, nursing has found powerful allies. The political groups active in promoting HIV research and care share many of nursing's values. Thus nurses are not the only ones calling for patient decision-making and public support of the sick. The success of political pressure groups, such as GMHC [Gay Men's Health Crisis] and ACT-UP [AIDS Coalition to Unleash Power], have helped bring nursing's values into the public arena.

The public arena has also seen a vigorous debate recently on the question of terminating treatment for the very ill. The nurses I interviewed support DNR (Do Not Resuscitate) orders and encourage their patients to plan their dying, including deciding what kinds of treatments to forego. The readiness of nurses to take on the

responsibility for discussing these issues with patients means that their perspective will become widely known and possibly very influential. Nurses in HIV care are already having an impact on how institutions deal with these sensitive matters.

Nurses in HIV care confront every day one of the major social puzzles of our time: how to deal with dying in a high-tech medical system. The solutions they propose are rooted in their profession's philosophy. It is a philosophy which accepts limitations, which desires the welfare of others, and which finds its reward in personal relationships. In caring for HIV infected patients, the nurses in this study practice and proselytize this philosophy.

V HIV Disease in New York City

The first report of cases of what would become known as HIV disease or AIDS appeared in the June 5, 1981 Morbidity and Mortality Weekly Report of the Centers for Disease Control of the U.S. Public Health Service. Five puzzling cases of *Pneumocystis carinii* pneumonia, an infection caused by a protozoan parasite, had been treated in Los Angeles. The five cases were all young men and all were homosexual. As the Weekly Report noted, *Pneumocystis carinii* pneumonia was a disease usually found in severely immunosuppressed patients. It was unusual to find it in five previously healthy individuals who did not have any apparent underlying immune deficiency.

At about the same time, physicians began diagnosing Kaposi's sarcoma, an uncommon malignancy in the U.S. at that time, in homosexual men. There were twenty cases in New York City and six in California. Eight of the patients had died, an unusually high mortality rate for this cancer. It commonly developed in elderly men of Mediterranean origin and its progress was usually quite slow.

Because of the unusual incidence of these diseases, ordinarily very rare, the CDC, in June 1981, began systematic surveillance for patients with these diseases. In July of that year, a task force was set up to characterize the syndrome itself, to determine the frequency of its occurrence in the population, to find out who was at risk of becoming ill, and why. The initial search was for laboratory-proven Kaposi's sarcoma and/or life-threatening opportunistic infections in previously healthy people between the ages of 15 and 60.

Meanwhile investigators were finding HIV disease in other

groups of the American population. During the fall of 1981, physicians in New York treated several cases of *Pneumocystis pneumonia* (commonly known as PCP) in heterosexual men and women who used intravenous drugs. The New York State Health Department reported a number of prisoners with similar symptoms. The condition was also found in patients with haemophilia A and in patients who emigrated from Haiti.

Epidemiologists found it difficult to connect all these different sets of patients in any way which would yield a clue to the syndrome's etiology. They had "no common medications, occupations, habits, or types of pets or any uniform antecedent history of personal or family illnesses with immunological implications" (Foege 1983:9). What did seem to be common to them all were behaviors which exposed them to blood and other bodily fluids. Multiple sex partners seemed relevant, as did anal intercourse. So did exposure to Factor VIII concentrates, a blood clotting protein. So did the use of needles.

What all patients evidenced was an immune defect which permitted opportunistic infections to take hold. These were frequently infections which a healthy immune system could successfully resist on its own or which, if they gained a toehold, could be routed by drugs. In patients with this new syndrome, however, these infections could spread and develop in unusual and alarming ways. The surprise doctors felt at the manifestations of this syndrome is noticeable in the following clinical comment on a patient who died of a brain abscess due to *Salmonella enteritidis* and *Nocardia asteroides*, both common bacteria:

This is an extraordinary case. Both organisms recovered from the brain abscess are handled by delayed immune mechanisms [The patient's] delayed-type immunity had been vitiated by the AID syndrome. [The patient] manifested two of the most frequently observed infectious complications, pulmonary pneumocystosis and oral thrush, as well as an unusual superinfection due to a species of nocardia and a bacterial infection due to a group of organisms, the salmonellae, being reported with increasing frequency. The site of the salmonella infection is very unusual indeed. To our knowledge this is the first report in this population of a salmonella brain abscess and the first report in any patient population of a combined nocardial-salmonella brain abscess. (Louria 1983:81)

In the absence of any identifiable agent, the CDC definition of this new disease in the 1980s relied on the presence of diseases indicative of defective cell-mediated immunity in patients with no known underlying cause for such a defect or any other reason for diminished resistance to that disease. Such diseases include tuberculosis (TB), oral candidiasis (a yeast), herpes zoster (shingles), and malignant neoplasms (tumors), such as Kaposi's sarcoma and various cancers of the lymph system. This syndrome was given the name Acquired Immune Deficiency Syndrome (AIDS), but with the identification of the Human Immunodeficiency Virus (HIV), it is now most commonly referred to as HIV disease or HIV.

What HIV disease does, researchers believe, is remove the body's defenses to the onslaught of infectious agents. Thus, what in a healthy person would be a mild illness, can become life-threatening

in an HIV infected patient. The viruses, bacteria and parasites which cause local and limited infections in healthy individuals become disseminated in the HIV infected patient and involve multiple organs.

In addition, few HIV infected patients have single infections. They may start with a cytomegaloviral infection, which is manifested primarily by fever, weight loss, and liver function abnormalities. After weeks or months of such symptoms, a patient may go on to develop pneumonia or colitis. The pneumonia may be due to cytomegalovirus (CMV) alone but it is often mixed with PCP (*Pneumocystis carinii* pneumonia). The colitis may also be mixed with herpes simplex, a virus which commonly causes blisters on the mouth or genital area, but which in HIV infected patients can spread throughout the body. *Mycobacterium avium-intracellulare* (MAI), a bacterial agent usually associated with the last stages of HIV infection, has been found causing disease along with CMV (cytomegalovirus) in the same intestinal tract. So also has *cryptosporidium*, a protozoa which causes diarrhea. (Armstrong 1983)

These infective agents are not new to medicine but their manifestations in HIV disease do not follow ordinary patterns. Infections occur in unusual organs and bodily systems and both virulence and response to treatment are unpredictable. One example is that one of the most common infections, that of candida (*monilia*), a yeast. It is usually found in the mouth or esophagus. It may respond to orally administered non-absorbed, anti-candida agents. But in some patients the infection persists until intravenous

amphotericin B or oral ketoconazole is administered. In others the infection is never controlled and either persists or relapses as soon as treatment stops. In still others it seems to resolve itself spontaneously. (Louria 1983:74)

The identification and isolation of the presumptive causative agent, the HIV virus, in 1984, led to blood tests for HIV infection. These tests do not reveal the virus itself; they reveal the presence of antibodies in the blood of individuals, first to viruses known to cause disease, and then to the HIV virus, and thus imply exposure to and infection with the virus itself. Several tests have to be performed before a diagnosis of HIV disease is reached. Thus,

the most widely used test, the enzyme-linked immunosorbent assay (ELISA) is used in conjunction with a confirmatory test, the Western blot, for HIV antibody. A person is classified and notified as being HIV infected after blood sample test results are positive in three tests - two successive ELISAs and one confirmatory Western blot (or another equally sensitive and confirmatory test). (Sloand 1992:2861)

There are gradations of HIV disease because HIV infected individuals may or may not show symptoms of infection. For this reason there is a distinction made between those who are diagnosed but asymptomatic, (HIV+ or HIV infected), those who are HIV+ or HIV infected and show only mild and transient symptoms, and those considered to be truly AIDS patients, who have an opportunistic infection or disease which meets CDC standards for a diagnosis of AIDS. Only the last group is considered to have full-blown AIDS, and this group is also divided now into those who are currently terminal

and those who are not.

The CDC standards for an HIV diagnosis are strict. A patient must either have one or more diseases known as "indicator" diseases without laboratory evidence of HIV infection, or must have tested positive for the HIV virus and have a disease associated with HIV disease but not necessarily an "indicator" disease. Indicator diseases are: candidiasis of the esophagus, trachea, bronchi or lungs; disseminated or extrapulmonary cryptococcosis; cryptosporidiosis with diarrhea; cytomegalovirus disease of an organ other than the liver, spleen, or lymph nodes; cytomegalovirus retinitis; herpes simplex virus causing a mucocutaneous ulcer that persists longer than one month; Kaposi's sarcoma in a patient less than 60 years of age; lymphoid interstitial pneumonia affecting a child less than 13 years of age; Mycobacterium avium complex or M. kansasii disease at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes; pneumocystis carinii pneumonia; progressive multifocal leukoencephalopathy; toxoplasmosis of the brain affecting a patient greater than one month in age. (Source: CDC 1992 revised classification system for HIV infection)

The diseases which can, when combined with a positive test for the HIV virus, be taken as a diagnosis of AIDS are as follows: bacterial infections of the following types affecting a child less than 13 years of age: septicemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity, caused by haemophius, Streptococcus, or other pyogenic bacteria; coccidioidomycosis at a site other than or in addition to lungs or cervical or hilar lymph nodes; HIV encephalopathy, also called HIV

dementia, AIDS dementia or subacute encephalitis due to HIV; histoplasmosis at a site other than or in addition to lungs or cervical or hilar lymph nodes; isosporiasis with diarrhea; Kaposi's sarcoma at any age; lymphoma of the brain at any age; other non-Hodgkin's Lymphoma of B-cell or other unknown immunologic phenotype and the following histologic types: a. small noncleaved lymphoma b. immunoblastic sarcoma; any mycobacterial disease caused by mycobacteria other than *M. tuberculosis* and extrapulmonary disease caused by *M. tuberculosis*; *Salmonella* septicemia, recurrent; HIV wasting disease. (Source: CDC 1992 revised classification system for HIV infection)

In November 1991, the CDC proposed new guidelines which use, in addition to the 1987 definition of AIDS described above, the number of T-helper cells, sometimes called Tcells or CD4 cells, in a patient's blood as an additional indicator of HIV disease. Those patients with Tcells under 200 and either a positive HIV test or a CDC approved indicator disease for AIDS are considered to have AIDS whether or not they manifest symptoms. Tcells or CD4 cells are lymphocytes which enhance the body's immune response. A low Tcell or CD4 count therefore means that the individual's ability to control infection is poor and indicates a defective immune system.

The proposed redefinition is a response to the change in population presenting with HIV infection. The original definition was drawn from experience with AIDS among homosexual men. Revisions of 1985 and 1987 added indicator diseases which had been subsequently identified as associated with AIDS. The 1987 definition added many patients, IV drug users in particular, to those diagnosed

as AIDS patients. The 1987 definition was severely criticized as being too restrictive, and the 1992 revision, with its inclusion of Tcell or CD4 count as a marker for AIDS, seeks to avoid the problem of adding newly recognized manifestations of HIV infection piecemeal. (Chang 1992)

This change in definition has important repercussions for HIV infected patients. It will expand the diagnosis of AIDS to many patients now considered only HIV+ or HIV infected because they have not had one of the opportunistic infections or diseases on the original CDC list. This has its greatest effect on women in whom the disease frequently manifests itself in gynecological infections and malignancies. Before the adoption of the Tcell or CD4 counts as criteria for AIDS, women with gynecological infections and malignancies and a positive HIV test, unless they also had a CDC recognized opportunistic infection, did not qualify for a diagnosis of full blown AIDS.

The use of Tcell count as a diagnostic criteria means that women suffering infections such as vaginal candidiasis, cervical cancer, and chronic pelvic inflammatory disease (PID), which are not now recognized as AIDS indicators the way PCP and Kaposi's sarcoma are, will, when combined with a Tcell count under 200 and a positive HIV test, be considered to have full blown AIDS. Some activists would like to see these conditions, without any reference to Tcell levels, considered sufficient for an AIDS diagnosis, but in the new regulations, such infections of the reproductive organs in women must be accompanied by Tcell counts below 200 and a positive HIV test to be considered AIDS.

These new guidelines were to be implemented in April of 1992 but it is now unclear when and whether the revised definition of AIDS will go into effect. Objections were raised that the new definition places undue burdens on local and state public health departments, that it excludes conditions causing serious morbidity in HIV infected women, that the emotional consequences of telling patients with CD4 counts that they have AIDS have not been explored, that the variability in testing for CD4 counts has not been accounted for, and that the new definition jeopardizes patients' confidentiality (AIDS ALERT 1992; Chang 1992). As a result of these objections, the CDC postponed the implementation of the guidelines, extended the public comment period and is, at this writing in July 1992, still reviewing letters from health professionals and AIDS advocates.

The continuing debate about who is to be counted as a true AIDS patient reveals the slipperiness of the diagnosis. A disease entity is usually well defined. In contrast, HIV disease moves along a continuum. In addition, the move to make Tcell status the critical standard will mean that some people currently healthy will be considered ill while others, already ill, will not be included in the same diagnostic group. The categories of HIV disease are distinctions of degree, not of kind.

This shift in CDC criteria is a response to the change in the population groups infected with HIV disease. The disease seemed at first to be a disease of young, gay men, and it was for a short time known as Gay Related Immune Disorder, or GRID. The next group known to be infected were intravenous drug users. Some

intravenous drug users (IVDUs) infected with HIV were women, but the majority were men. It was suggested that it would be through male IVDUs that the disease would spread to heterosexual women, and that has been the pattern. Partners of IVDUs are the largest growing number of HIV infected patients in New York City.

Because New York City has the country's largest populations of gay men and IVDUs, it has the largest number of adult HIV cases in the nation. As of August 1991, 33,580 cases have been diagnosed. Of these, 28,571 are male; 5,009 are female. A total of 21,276 patients have died. In addition, there have been 813 cases of pediatric AIDS, of which 467 have died. (Source: NYC Department of Health) Whether these figures are accurate is somewhat questionable. They are thought to be too low. There is a lag in reporting cases and some cases are lost in the system. Patients die of other diseases or trauma and are never diagnosed. Women, particularly, are unreported because their infections often do not fit the CDC guidelines.

The infections which patients in New York City have presented and which fit the CDC criteria are as follows:

Frequency of Diseases Diagnosed* in Adult Cases

(Diagnoses seen in at least 1% of cases)

Diagnosis	% of Cumulative Cases
1. Pneumocystis carinii pneumonia	58
2. Kaposi's sarcoma	13
3. Candida esophagitis	7
4. Cryptococcal meningitis	7
5. Toxoplasmosis	5

6. HIV Wasting Syndrome	5
7. Mycobacterium avium-intracellulare	4
8. HIV encephalopathy	3
9. Cytomegalovirus disease	3
10. M. Tuberculosis (extrapulmonary)	3
11. Lymphomas	2
12. Herpes Simplex virus	2
13. Cryptosporidiosis	2
14. Cytomegalovirus retinitis	2
15. Mycobacterium, other**	1

* Some cases have multiple diagnoses

** includes Mycobacterium, of other species or unidentified species, disseminated or extrapulmonary

Source: New York City AIDS Surveillance Report April-June 1991
pg.7

These aggregate figures mask what are significant differences in the incidence of HIV disease in different areas of New York City. In the Bronx the rate of infection per 100,000 ranges from 184 in Kingsbridge and Riverdale to 1380 in Hunts Point and Mott Haven. In Manhattan, Chelsea and Clinton show a rate per 100,000 of 2184, compared to 408 in the Upper East Side. The other boroughs show similar though less dramatic discrepancies. Some areas have three to four times the infection rates of others. (New York City Department of Health 1991)

These differences in incidence rates follow racial, ethnic, sexual and socio-economic neighborhood patterns. The Hunts Point and Mott Haven areas in the Bronx are very poor and almost completely

black and Hispanic. Kingsbridge and Riverdale are middle class and predominantly white. Chelsea and Clinton, along with Greenwich Village which has an infection rate of 1824, are where Manhattan's gay community lives. The Upper East Side is rich and white. Thus the incidence of the disease is not uniform across the city. Pockets of infection, where homosexuals, the poor, and minorities live, are interspersed with areas where relatively few AIDS cases are to be found.

Because HIV disease in New York City is at present a disease of marginal groups, it has been difficult to rally people and institutions to the challenge the disease presents. Indeed from the first there has been an effort to believe that not only are these groups responsible for their illness but that they would be the only ones affected. As Kenneth Ludmerer notes:

When medicine stands ineffective in the face of dread disease, the temptation to explain disease in cultural terms is pervasive and overwhelming. Society gains comfort and hope in feeling that outsiders or socially disapproved groups are in some way responsible for the outbreak of disease. If those groups can be placed beyond the pale of society - via stigmatization, isolation quarantine, or genocide - the epidemic might be brought under control. (1989:9)

In New York City, as in San Francisco, the gay community took charge of the effort to make HIV disease an issue every citizen should know about and be concerned about. The gay community had the resources to do this because they "congregated in territorial communities, often called 'gay ghettos' (Gorman 1986:161). Gay

institutions and businesses of all kinds thrive within the community. Thus homosexuals had an organizational base, a sense of community, and political and financial know-how which they mobilized to respond to HIV disease.

Two organizations are at the forefront of the effort. The Gay Men's Health Crisis, (GMHC), which was organized by politically astute activists, is the largest, best funded, best known, most effective organization in the city dedicated to the care of HIV infected patients. It runs a raft of programs, mostly staffed by volunteers, which provide information on the disease, promote the cause of HIV care, and supply 'persons with AIDS' [PWAs] with volunteer buddies who help them with chores and daily living. A more radical organization, ACT-UP, [AIDS Coalition to Unleash Power], is at the forefront of political demonstrations on behalf of HIV infected patients, pressuring governmental and medical bureaucrats to relax the rules on drug approvals, promoting needle exchange programs for addicts, and proselytizing the use of condoms.

Because the minority populations lack the community ties which enabled the gay community to organize its own response to HIV disease, there are no comparable institutions in poor and minority neighborhoods. There are efforts to set up education programs in minority areas but they do not have the ability to tap into funding nor to run effective PR campaigns for volunteers. GMHC makes an effort to include minorities and women in their programs but the majority of the patients they care for are young, gay, white men.

Both gay men and IVDUs pose special problems for care. New

York City has always tolerated different social behaviors and as a result, has a high number of single residents, many of them immigrants from other parts of the country and abroad. "Its percentage of unmarried men at the start of the decade was second only to San Francisco's, and the total number was far higher" (Killip1989:77). Intravenous drug users are also frequently on their own; the homeless crisis of the 1980s put many of them on the street.

Being sick without a family support system is difficult and expensive. Many of the services an ill person needs revolve around ordinary domestic requirements, such as cooking, shopping, paying the bills, which family members can provide for the ill person. Without family support, the patient becomes dependent on formal services, if there are any, provided by the state. (Vladeck 1989:87)

The new wave of HIV infected patients is equally in need of homemaker services. Women are the fastest growing segment of the AIDS population. They are often the caretakers of families, and when they become ill, those dependent on them suffer. Some have ill partners already; some have ill children. They cannot take care of others while ill themselves.

The needs of HIV infected patients for on-going care related to daily living, in addition to medical treatment, run counter to the thrust of health care provision in the United States. The American healthcare system is organized around acute care. It expects that patients will be treated in a relatively quick time and released back into society where they will convalesce on their own. The system is therefore quite unprepared to deal with an infection like HIV disease

which does not present clinically clear-cut health problems and which infects groups of citizens who need many and diverse services in order to live with their disease.

In addition, American public policy has always emphasized cash assistance over institutionalization. "The guiding principle has been to give people cash supplemented with specific services" (Vladeck 1989:88). Patients are left largely to themselves to find and arrange for the services they need, while the cash benefit part of the arrangement has always been low, because it was assumed that disabled people have friends and neighbors on whom they can rely for support. Since this is not true for many or most HIV infected patients, this strategy falls far short of enabling people with HIV disease to meet their daily needs.

Furthermore there has been a concerted effort, particularly in New York and California, the states hit hardest by HIV disease, to transfer as much as possible of the costs associated with the care of dependent populations to Medicaid. The reason for doing this is that 50% of Medicaid costs are paid by the Federal government. For AIDS care, which is expensive, moving it to Medicaid saves the state a great deal of money. It has been estimated that the average lifetime medical expenses per HIV patient in the United States is somewhere between \$65,000 and \$80,000 (Cooper 1989:100). These numbers are now disputed but even if the cost drops, the rising incidence of HIV disease means expenditures must increase. In New York State, therefore, inventive programming has resulted in such creations as the HIV health related facility, (AIDS HRF), which is "an attempt to provide a service that is essentially residential and supervisory in

the guise of a Medicaid-reimbursable health facility." (Vladeck 1989:90)

The consequences of this effort to define institutions as health facilities in order to garner Medicaid reimbursements are important. First, being a part of Medicaid necessitates a level of reporting and oversight which in itself is a significant cost. Second, it means that the criteria for admission have to be clinical criteria even when the circumstances which make admission necessary are non-medical. As Vladeck comments:

Ironically, it may also mean that residents of the facility get less than optimal medical care. As has been the case with nursing homes, policymakers require such facilities to provide a minimal level of health-related services in order to qualify for status as Medicaid-reimbursable health facilities; but they are then reluctant to pay for very extensive services, which would be irrationally expensive. In this case, the mediocre may well drive out the good: the provision of adequate medical supervision may in practice be more difficult in facilities with limited health services than in a purely residential setting into which targeted services can be brought on an as-needed basis. (1989:90)

According to Vladeck, the effort to squeeze HIV services into the Medicaid box has distorted and delayed needed programs. In New York State the primary responsibility for case management of persons with HIV disease has been assigned to hospitals designated as AIDS centers. This was done because the hospitals were already conduits for Medicaid funds. Whether hospitals were the best

environment in which to establish the programs, and whether the hospitals had the capacity to manage these programs was not a concern (Levine 1990).

The state's reliance on Medicaid also has direct consequences for patients. In order to qualify for Medicaid, patients with HIV-related illnesses must either spend down their money to the poverty level or have advanced already to clinically defined, full-blown AIDS. Eligibility and therefore the criteria for eligibility, including the CDC guidelines for diagnosis of HIV disease, become part of the struggle for Medicaid reimbursement.

The gyrations state officials have performed in order to fit HIV programs into existing health financing programs reflect the fact that Medicaid is about the only mechanism currently available to pay for these costs. The federal government, during the Reagan years, successfully reduced federal support for human services of all kinds. It has provided funds for AIDS on a sharply increased rate since 1986, but these monies have been primarily directed at research, education, and surveillance. The federal government has not provided money for the supportive care of the ill.

HIV disease thus appeared at a time when the medical system was shrinking. In New York State health planners decided, in the early 1980s, that there would be declining demand for in-hospital stays and a corresponding increase in demand for ambulatory services. Between 1980 and 1985, therefore, 1800 beds in New York City hospitals were eliminated.

As a result hospitals in New York City show the highest average census figures of any metropolitan area in the country. Under the

onslaught of drug abuse, particularly crack, AIDS, TB, and sexually transmitted diseases, (STDs), census figures for city hospitals range around 90% and a few report a census count over 100%. Such crowding results in poor patient care. As Killip comments:

As anyone who is in the management of a large hospital (especially one with a busy emergency room) knows, when average census approaches 90 percent of capacity or above, the entire system is stressed. Flexibility to meet unexpected emergencies, such as equipment failure, personnel absences, or high volume, is limited, and patient care suffers. (1989:76)

Municipal hospitals in New York City are particularly stressed because they provide medical care to the poor and minority populations of the city, exactly the ones most affected by the HIV virus. They are also the hospitals of last resort for HIV infected patients who have exhausted their insurance benefits and/or personal savings. Municipal hospitals carry a disproportionate load. They have 8288 beds, compared to 27,500 for voluntary hospitals, but in a census taken in 1989, 3.9% of voluntary hospital beds were filled with HIV patients compared to 7.1% of municipal hospital beds. (Killip 1989:78)

The change in character of the HIV infected patient from white, gay male to poor and minority IVDU user and/or partner is a particular challenge to hospital management. When large numbers of substance abuse patients are admitted, "pushers begin strolling the halls. Wheeling and dealing goes on in the corridors and stairwells. Patients are 'shooting up', and the atmosphere of a devoted health-care environment is easily subverted." (Killip

1989:79). Before HIV disease, drug users were intermittent and infrequent clients of the health care system. They tended to come to the hospital for emergency treatment and then disappear. With HIV, they have become a large and growing percentage of all hospital admissions, bringing with them many management problems. For nurses particularly, these patients can be frustrating. For example, they may not have the educational background to understand explanations couched in scientific terms. One nurse I interviewed said that she often drew pictures or used handy objects, like water cups, to illustrate what she told her patients about HIV disease. IVDUs often lead disorganized lives, so compliance and follow up may not be complete. They can be resistant to suggestion and exhortation. Thus, in general, teaching and counseling IVDUs about HIV disease and the kinds of behavior changes which prevent further infections is more difficult than with white, male, gay patients. One administrator of a dedicated AIDS unit told me that teaching her staff what to expect from and how to care for the IVDU patient was her top priority.

In addition, there is considerable distrust between minority communities and government in New York City. Some African-American groups have gone so far as to claim that HIV disease is some form of biological genocide (Dumpson 1989). This complicates care in many ways. Patients come to the hospital; there is nowhere else to go. But they may not be candid about their history and may not be receptive to the recommendations of the staff.

From a number of directions then, hospitals are under increased and unremitting stress and so are the personnel who staff

them. Doctors are under pressure to produce treatments for a disease which remains elusive and difficult to control. The arsenal of drugs which have proven so effective against infectious disease in the last fifty years are relatively ineffective in the case of HIV. There are, at this writing, only two approved drugs used to control HIV disease, one is azidothymidine, (AZT), the other is 2',3'-dideoxyinosine, (DDI). Both work in a similar way to prevent the replication of the HIV virus. Both have proved helpful in prolonging life but there are serious side-effects to both as well. Neither is a cure.

The failure of the medical profession so far to cure HIV disease erodes its authority and challenges doctors' power. Doctors run the American health care system (Starr 1982). Only they are allowed to prescribe, except in certain very specific circumstances where a doctor is not available. It is their orders which are followed in hospitals. Decision making positions in hospitals and accrediting agencies are filled with doctors, and they have successfully challenged many attempts by other health care personnel, particularly nurses, to be allowed to practice direct care as independent practitioners.

The hierarchical organization of the health care professions in America puts doctors at the apex of the structure because they claim the knowledge and expertise which cures. The appearance of a disease which continues to defie and confound them calls into question the unspoken but real social contract through which doctors occupy a privileged position in American society.

In addition, the fear of the disease among health personnel

precipitated bizarre behavior towards HIV infected patients, particularly in the early stages of the disease. Surveys of doctors and nurses indicate, even now, a relatively "high degree of anxiety or discomfort, homophobia and fear of contagion." (Gee 1989:51; Schwarz 1989) The prevalence of such attitudes affects patient care and relations among colleagues.

Complicating relations among health care personnel can be differing views on such ethical issues as whether patients and/or health care workers should be required to be tested for the HIV virus, whether HIV infected patients should be reported to public health authorities, whether HIV infected health care workers should be allowed to practice, and whether sexual contacts of HIV infected patients should be notified that they may be at risk. New York State currently supports voluntary testing and protects patients' confidentiality. The state is also concerned to protect HIV infected patients and those workers, particularly health care workers who are HIV infected, from discrimination.

Because HIV disease is presently incurable, and because treatment prolongs life without necessarily improving its quality, questions about the resuscitation of dying patients and intensive care for gravely ill HIV infected patients divide health care workers and complicate care. In general, because their training is to be aggressive and pursue every avenue of treatment, many doctors are reluctant to discuss Do Not Resuscitate, (DNR), orders with their patients. Many of them also have difficulty prescribing large amounts of pain killer when they know that the pain killer may hasten the patient's death. Because doctors are the ones in charge, what they hold on these

ethical questions can affect patient care as well as their relations with their colleagues.

Another ethical issue which can produce discord within the health care unit is the question of duty to care (Jonsen 1990). Because HIV disease is contagious, there are some who claim the right to refuse to care for HIV infected patients. Refusing to care for HIV infected patients is easier for doctors than for other health professionals because, unless they are hospital-based, many of them can restrict their practice to particular groups. Many already restrict the number of Medicaid patients they accept, and this in itself will limit their exposure to HIV infected patients. That some doctors and other health care workers, nurses among them, can openly acknowledge that they feel no obligation to care for HIV infected patients is another indication that the social contract between the public and those charged with the care of the sick is being revised (Gee 1989; Schwarz 1989).

HIV disease in New York City has made visible the fragmentation and disarray of the health care system. Health care for the poor is not the same as health care for the rich. Neither is it the same for groups outside the boundaries of mainstream culture. The effort to provide care, limited as it is, puts enormous strain on an already overburdened system.

It places particular strains on nurses who are the links between the individual patient and the health system itself, yet who have to work within the system. What follows is an account of how one group of nurses is providing care within a system beset by social and financial challenge. HIV disease has brought into the system

patients who need an extraordinary concentration of care yet who do not represent what is culturally valued in American society. The disease which afflicts them poses a substantial risk to their caregivers. They are generally young, far too young to die, according to our expectations of how long people should live, but they are dying. They challenge closely held beliefs about medicine and about social worth.

Thus HIV disease is a catalyst for further fragmentation of the health care system. It disturbs the way care has been paid for, it evades the arsenal medicine uses against it, and it brings into the system groups of patients who have not until now been numerous. HIV disease thus upsets usual practices, cognitive habits, and affective inclinations by asking who is worthy of care, what kind of care should be provided, and who should do it.

VI The Environment of HIV Care in New York City

Medical care never operates in a vacuum; its provision depends on the larger social environment where political decisions are made. So it is that HIV care is affected by social and political currents within the body politic and is subject to the ongoing debates and divisions within the healthcare system as well. In addition, because of the nature of HIV disease, the organization of care for HIV infected patients has been particularly vulnerable to pressure from both the left and the right. Advocates of HIV infected patients base their claims for more funding and more programs on the manifest needs of those infected; their opposition focuses more on the cost of providing care.

The struggle centers on access to care. Unless an individual is rich enough to pay for care without recourse to an insurance plan, or is insured under a health plan sponsored by an employer, the only care available is that provided by public institutions, which have always been and are now financially precarious. Relying on public institutions is risky. Programs are subject to continual review and revision, and fiscal considerations are frequently more important than the proper provision of care.

Access to health care in the United States is linked to age, disability, employment and to diagnoses of specific diseases, such as renal disease. There has never been a commitment to providing health care for all. Specific groups, the elderly, the poor, or mothers and children have been targeted from time to time, but no comprehensive effort to provide health care for all citizens has ever gotten off the drawing board. Therefore, HIV care represents a

challenge to the conceptual underpinnings of the American health care system, which envisioned treatment clustering at the beginning and end of life with only intermittent care in between. HIV disease is a chronic disease with unpredictable acute manifestations. Such a disease had not been anticipated in structuring payment and provision of care. It threw off the procedures already established for anticipating medical care costs. And until sufficient research was done on the actual costs of caring for HIV infected patients, the tendency was to use the highest estimates as the basis for future planning.

From the beginning, the question of the cost of care for HIV infected patients has been used by both sides to gain advantage. Advocates for HIV infected patients have used the estimates of high cost as a reason for public support; opponents of increased funding have used the same figures to restrict and restrain benefits.

The figures themselves have rarely come under scrutiny, but as Daniel Fox and Emily Thomas argue in a 1990 article, the numbers which were bandied about often had little relation to reality. Between 1983 and 1985, estimates erred on the high side. A widely accepted number from the CDC was that from diagnosis to death, an AIDS patient would cost \$147,000. This figure was sullied because much of the data on which it was based came from New York City hospitals which had large numbers of HIV infected patients who couldn't be discharged because they had nowhere to go. This drove up the aggregate number of days spent per patient in the hospital. Using this data for a model for the United States as a whole was a mistake.

Indeed, hospital figures for the cost of HIV care seem to have been arrived at more by guess work than sober analysis. According to Fox and Thomas, many hospitals began "with their ordinary reimbursement rates and then added estimates, based on staff reports of their use of time and materials, for additional nursing, social work, and housekeeping services" (1990:200). Groups of workers within hospitals insisted that caring for HIV infected patients was more labor intensive than caring for patients in other units. One of the nurses in this study was asked to calculate the number of nursing hours needed per HIV infected patient by the hospital she worked at; she estimated, without any substantive research, that each patient required eleven hours of nursing care per day. This is an absurdly high figure, but it was accepted uncritically and became part of the hospital's standard cost estimation and planning projections.

Such projections and their incorporation into state reimbursement schedules were exactly what hospital officials in the 1980s wanted to see. Hospital and insurance executives publicly commented on the high cost of HIV disease because they were being pushed by owners and trustees, state regulators, and third party payers to reduce costs. Persons with AIDS [PWAs], whatever the source of their infection, became the whipping boys for the financial problems of the hospitals. HIV disease became a proxy for the problems of health care finance. (Bartlett 1990)

In 1985, the high cost of HIV care was disputed; studies, particularly that of Scitovsky (1986) for the Palo Alto Medical Foundation, found that the costs of HIV care were little different

from other diseases. In 1988, Emily Thomas and Daniel Fox looked at four hospitals in metropolitan New York City and concluded that the cost for an AIDS patient, from diagnosis to death, was around \$38,000, much different from the \$147,000 of the CDC. On the basis of these new figures, therefore, the federal government refused to establish special and more generous reimbursement rates for the care of HIV infected patients.

In 1985, however, New York State raised its reimbursement rates for HIV infected patients by 30% for routine care and 20% for ancillaries. This move was designed to force third party payers to finance a hospital based case management system for HIV infected patients. AIDS center hospitals, which met certain state requirements, were designated as the managers of the system and the increased reimbursement rate was an inducement to take on the care of HIV infected patients. No municipal hospital is currently an AIDS center because of the expenses involved in meeting the requirements, but city hospitals may reconsider because the state is thinking of lowering DRGs [Diagnosis Related Groups] for AIDS patients in noncenter hospitals. (Levine 1990)

The increase in reimbursements, although it had the salutary effect of increasing beds and clinics for HIV infected patients, also had the unanticipated consequence of making HIV disease something of a lightning rod for resentment among administrators and clinicians because it challenged other diseases for scarce resources. With the incidence of HIV disease rising fast, particularly among the poor and the uninsured, the question of cost quickly focused on the drain of public funds and the burden placed on public sector financing.

And it was on the public sector that an increasing number of HIV infected patients turned for care. Private health insurance in the United States depends on employment. When most HIV infected patients were young, white and gay, private insurance did provide for many of them, but as the epidemic gained strength, employers found ways to limit or deny coverage. One tactic was to withdraw from widely based group plans and self-insure. Self-insurance plans are allowed to refuse coverage for certain diseases and certain treatments. Insurers also tried to limit liability for HIV disease by denying coverage for HIV-linked illnesses, requiring HIV tests before insuring, and asking about applicants' drug use and sexual practices.

Legislation was enacted by both the federal and state governments to prevent the wholesale dumping of HIV infected patients from insurance plans. One effort centered on preventing testing by insurance companies. New York State's legislation to prevent HIV testing by insurers was just recently struck down by the courts, on the grounds that the regulatory agencies had exceeded their authority. (Fox and Thomas 1990)

The federal government passed the Consolidated Omnibus Budget Reconciliation Act or COBRA of 1985 which established continuation requirements; employers could not terminate insurance coverage when an employee left a job. New York State, in addition, passed a law requiring employers to permit departing employees to convert from a group to an individual policy. This was meant to protect members of group policies whose health needs might mean that they would have difficulty finding other coverage. Both continuation and conversion requirements falter on the requirement

that the employee pays the premiums. These can be higher than when the employee had a job; and if the employee doesn't have a job, the employee might not have the money to pay the premium.

This contingency is being addressed in a pilot program in Michigan which pays PWA's premiums so that they won't apply for public coverage. Other states, but not New York, have established insurance pools for PWAs and other uninsureds. One drawback to the pool plan is that the shortfalls, and there are inevitably shortfalls, are paid up by people purchasing traditional insurance; the self-insured are not required to contribute. (Fox and Thomas 1990)

As a result of these efforts to avoid paying for the cost of HIV care, many PWAs were thrown onto the public system. In 1985, only 45% of HIV patients admitted to private hospitals had private insurance. Only 7% of those admitted to public hospitals had private insurance. (Killip 1989)

Without private insurance, HIV infected patients turn to Medicare and Medicaid for assistance with medical costs. Medicare coverage is virtually nonexistent, although Medicare is supposed to provide care for disabled workers who meet certain work history requirements. The technique Medicare uses to deny benefits is to delay. There is a lengthy application process requiring time and energy that a PWA may not have. As Joan R., a research nurse in a voluntary hospital, said:

I think what most of them need is having enough people around who they can talk to, just having them available to help them with finances, discrimination, housing issues.

They need somebody to be an advocate for them because they're exhausted from the virus. A lot of them get fatigued and yet they have to go out and deal with an employer, then disability, then getting into drug treatment, dealing with housing problems. It's hard.

To become eligible for Medicare benefits, an individual must first apply for Social Security Disability Income (SSDI) cash benefits. SSDI benefits start five months after a person is disabled; then there is a wait for two years before Medicare benefits starts, a total of 29 months from the first request to the implementation. In 29 months, an HIV infected patient may well be dead. It is not surprising then that access to treatment was at the top of the list of ethical issues for the nurses in this study: 66% for those interviewed, 63% for those surveyed.

There have been proposals to reduce or eliminate this waiting period for PWAs, but opponents cite cost and fairness. They contend that waiving the waiting period for PWAs would bring demands from people suffering from other diseases and all the terminally ill. The estimates of the cost of waiving the waiting period range from two to eight billion dollars for PWAs for five years to thirty five to forty five million for all the disabled for five years.

Chances for eliminating the Medicare waiting period are not good, although in the meantime, money is still being spent, but on the state, not the federal level. Medicaid, the federal/state program for medical for the poor and indigent, is the program which is the most common final resort of PWAs.

PWAs become eligible for Medicaid, if they are not already

enrolled before becoming infected, when they are deemed disabled. Variations in eligibility and variations in benefits, such as how many hospital days are covered per year, are widespread. New York State's Medicaid program is among the most generous, but again, the application process is bureaucratic and burdensome, and the number of personnel assigned to the New York City department charged with coordinating benefits for PWAs has not kept pace with the number of HIV infected patients. One nurse whose patients were all Medicaid supported said that he arranged for a terminal patient to go home and discovered a few days later that the man's electricity had been turned off through some snafu in the welfare department. The patient was sitting in the dark, without the energy to make a telephone call and track down the person who could get his electricity turned back on.

In New York City, of course, no one in need of care but lacking insurance or a Medicaid card is turned away from a municipal hospital. But because the demand for care is greater than the supply, the wait for care can be long whether in the emergency room, the clinic or the ward. And because the hospitals are continually trying to cut costs, the level of care may be minimal.

In the 1980s, just when HIV disease surfaced, the American welfare state began to shrink. Governmental programs of all kinds found their budgets cut; hospitals most of all. Cost containment measures, specifically DRGs [Diagnosis Related Groups], propelled hospitals into a frenzy of cost cutting. Hospitals moved into ambulatory care, cut the number of days patients could stay, and generally increased the pressure to do more in less time.

New York City hospitals have the lowest financial operating margins in the country (Killip 1989), and therefore felt the greatest incentive to find ways to lower costs. Faced with demands that could not have been foreseen a decade ago, New York City hospitals entered a traumatic time when demands swiftly outpaced resources. The situation in many hospitals became chaotic. In 1987, 52% of all admissions to hospital were unscheduled; patients simply appeared. 66% of admissions to municipal hospitals and 46% of admissions to voluntary hospitals came through the ER [emergency room]. Such a situation made anticipation difficult and planning an exercise in hope, if not an exercise in futility. In 1987, the Bigel Institute for Health Policy issued a report on health care in New York City which documented the conditions under which the system was struggling. The situation was described as "medical gridlock". (Killip 1989)

Hospital personnel were the first to feel the contraction of funds in the system because low operating margins mean "a continuous scrutiny of personnel costs, the largest item in any hospital budget" (Killip 1990:76). Layoffs meant that there were fewer people to perform the tasks needed. Patients found that appointments had to be scheduled weeks, if not months ahead. Higher patient:caregiver ratios for inpatient units were established, and with same day admission for many procedures and shorter stays in hospital overall, nursing staff particularly found that there was less time available to do all that had to be done. Everything had to be rushed. Stephanie C., who has worked at a municipal hospital for over twenty years, describes the New York City medical system this way:

I call the city hospitals a deprived system because the resources are always dwindling. We have to be more and more resourceful about getting the things we need. It's not supplies, we have enough gloves etc.; it's that we have no space, no privacy, no place to interview patients. It's personnel, it's some of the niceties, some of the things that would make the process of being sick and in the hospital nicer, are missing. Like we don't have enough sheets, and there aren't enough pillows. The pillows walk out the front door. We use paper towels now because the towels were all stolen. The food is dreadful. I feel badly for our patients who have to spend, sometimes, months in the hospital. I feel for them. I think, "Oh I wish you could have a flower on your tray, or that the plastic tray which holds the food was not chipped or stained."

This scenario continues. Many of the nurses in this study who could not find time to be interviewed a second time said that their workloads had increased immeasurably in the interval between the first time I contacted them and the second. There is continual pressure to complete tasks quickly and move onto the next. The temptation to treat patients as tasks to be finished rather than people to be cared for is strong. The increased tempo of work not unnaturally brought in its wake an increase in the number of accidents. There were more needlesticks, more lacerations, more scalpel wounds in the operating rooms, vial breakage in the labs, splashes of human blood and other fluids onto caregivers. Columbia-Presbyterian Hospital reports one exposure to body fluids a day, and

those are the ones which are reported (Karpen 1992a).

This was the situation that patients infected with the HIV virus found when they approached the medical system in New York City for care. There were not enough beds and there are not enough beds today. Hospital capacity is still shrinking even though the New York City AIDS Task Force estimated that by 1993, five thousand beds, almost one fifth of the city's capacity, will be occupied by patients with HIV disease (Levine 1990).

Hospital staff were not infrequently insensitive to the social ramifications of treatment for HIV disease. One clinic for HIV infected patients was called Zidovudine Clinic, thereby announcing to the world at large what the people entering the clinic had (Karpen 1992a). The name was later changed to Infectious Disease Therapy Clinic, although now the cover of infectious disease has been used so often that it is quite often taken to mean HIV disease and it frequently does. Advertisements for AIDS units in New York City newspapers call for infectious disease nurses.

Medical staff in hospitals could go beyond insensitive to hostile. In one survey of hospital residents it was found that 23% said they would not take care of PWAs, if given the choice. Forty two percent (42%) said they would not care for PWAs who were also IVDUs [Intravenous drug user] (Karpen 1992b). Even patients with private insurance had difficulty finding doctors who were willing to care for them, and in two instances described to me by nurses in this study, when the insurance ran out, the patient was unceremoniously switched to a municipal hospital from a voluntary one.

Sixty eight percent (68%) of the nurses interviewed for this

study and 57% of those surveyed said that working with colleagues who did not share their philosophy of care was one of the difficulties they faced. As Alice M., who worked in an ambulatory clinic said, "There's a lot of inhumanity to man here." As Gloria R., a midwife, said:

I remember at [a city hospital] when we first got [HIV infected] patients, these poor souls were stuck in isolation.

Nobody wanted to go near them, like the plague. It was awful.

In the early days, staff often gowned up before going into an HIV infected patient's room. Even in 1990, I saw a housekeeper put on two masks and two pairs of gloves before going into mop a room in an AIDS unit. One nurse reported that she saw another come out of an AIDS patient's room and wipe the soles of her shoes with alcohol. There were instances of meals left outside doors and beds unmade and baths not given. Patients were left alone to fend for themselves. Reluctance on the part of other nursing staff, particularly licensed practical nurses and nurse's aides who do much of the physical care on hospital units, to care for HIV infected patients can mean that basic sanitary procedures are neglected (Gwartney 1992). Since infection control is critical to HIV care, this neglect can have serious consequences for patients.

At the time of my interviews the situation had improved. Most of the most obvious forms of discrimination had disappeared, according to my informants, but still there existed a decided reluctance to care for HIV infected patients. As Emma J. said:

I think it's a little easier now than in the beginning. I think because there is less hysteria, but you never know where that

hysteria is going to come from. It crops up everywhere, and it crops up with people you thought you had educated. It comes up here [in the hospital]. Suddenly I see nurses who went through AIDS 101 garbed to the hilt going into a patient who has nothing they are going to catch by looking at him or being in the room with him. I say to them, "What is this? Why?" And they tell me that they're not sure what he's got so just to make sure, they're going to wear everything they can put on their bodies.

I did hear of nurses who could not tell their families that they took care of HIV infected patients. I was told of one nurse who stuck herself with a needle and was told by her husband to sleep on the sofa in the living room until her AIDS test came back. One nurse in this study said of her own husband:

He is adamant. I don't discuss it with him. He can't deal with it, period. It's fortunate for our relationship that I'm not caring for patients directly right now because he would not be able to deal with it at all. He knows that I'm occasionally involved in direct patient care, but he doesn't talk about it. He doesn't want to talk about it, so we don't even begin to communicate about it.

I heard of per diem nurses arriving on the AIDS unit and refusing to work. I heard of nurses making themselves so unpleasant to HIV infected patients that the patients asked that the nurse be assigned to others. I heard of difficulties in recruiting nurses to the AIDS units. In describing how they took care of patients, the nurses in this study often compared how they practiced with others who

were unsympathetic and unhelpful to HIV infected patients. Several noted that the behavior of other staff spurred them into becoming involved with HIV infected patients.

Forty six percent (46%) of both the nurses interviewed and those surveyed felt that some of the social stigma attached to HIV disease was transferred to them. Friends, family and colleagues questioned their decision to work in HIV care. Some nurses are reluctant to advertise their involvement with HIV disease. One nurse told me she didn't want to become 'Ms. AIDS' in her apartment house. Another, who lived in a suburb, said:

There are so many society pressures. I live in a town which is very middle class. I really thought about whether or not I could have AIDS magazines sent to my house because my postman may not deliver it, or my neighbors might see it, and I know that in that community there is not a great acceptance. I have tried to work through some of that in my local church by offering my services to give lectures and let people know. Nobody has taken it up.

Again, public perception has recently changed and nurses dedicated to HIV care are now more likely to be honored than reviled, but as fears of AIDS subside, fears of TB have risen. As a nurse said to me recently, "it [TB] is just like the early days of HIV."

The nurses in this study did not expect to totally change the environment in which they worked, but where they could, in their own practice, as a model for others, they projected a different attitude and a different ethic. As Maria M. said about her work as a staff nurse in an AIDS unit in a municipal hospital:

I go in there [to the patient] because I want to be there. It's evident that I don't have prejudice, I don't mind that they're HIV infected. I sit on the bed, I talk to them, I put my arms around them, be human with them. I try to deal with them so it doesn't matter that they have HIV disease or AIDS. I think that's probably our biggest contribution on our floor to these patients.

Because so many of the nurses in this study, twenty four of the nurses interviewed, have case management and inservice education responsibilities, they are in a position to influence other nurses. This they try to do through discussion, videos, demonstration, and exhortation. Bob G. described the varieties of approaches he takes if he finds a nurse treating an HIV infected patient badly:

I have alternatives. I can bring that person aside and talk to them personally. I can be very hard nosed. I'm a head nurse, and I can say, "You did wrong, blah, blah, blah, and you're making me real angry." Sometimes it takes that. I also can speak to the head nurse on the unit and get her involved. If I see somebody being abused, I will try to alleviate the situation because I usually know the patient better than they do, and so the patient will talk to me. If I learn that a patient hasn't had his bed changed and he deserved it, I make sure the head nurse is aware. That's one way of doing it. Right now I'm showing a film around the hospital about ethical dilemmas in dealing with AIDS patients. The film asks you to pretend you're a head nurse, and a pregnant nurse comes up, and says, "Don't give me any of the AIDS patients because I'm pregnant."

What do you do? That's on the film, and then you stop the tape and talk about it. People will talk and frustrations will come out. It's a values clarification tape, and so I go to all the floors and I try to get them that way. It's a way of ensuring good patient care, a very indirect way. There's the direct didactic way, and then a way of interacting with these people in a humane way, so they have a model.

These nurses do not expect miracles. Their slogan is "to make a difference" not "to change the world". But the fact that the nurses in this study, both those interviewed and those in the survey, have not succumbed to the institutional malaise which surrounds them is a tribute to their training, their tenacity, and the fact that their perseverance brings them immense intellectual and emotional rewards.

VII Meeting HIV Disease

By now, in 1992, HIV disease is well known. It has had a name for almost a decade, the causative agent has been identified to the satisfaction of most, if not all, practitioners, and each year adds something to what has already been established.

But at the beginning there was simply the sense that something unusual was going on. Patients came into the hospital with pneumonia and died when they shouldn't have. They wasted away. They developed unusual cancers. They had fevers which went right off the charts. And they were young.

At first there weren't enough of them to attract the attention of epidemiologists; they were scattered in different hospitals, and until 1981, no one was collecting data on a systematic basis. The New York City AIDS Surveillance department notes only forty six cases of AIDS before 1981.

They were just the patients nurses wondered about and later, when HIV disease was identified, decided that they must have been infected. Bette V., a nurse who went on to become the head of an AIDS unit and then a director of nursing in a voluntary hospital, recalled the era of the earliest HIV patients thus:

In 1980 when the first AIDS patients arrived, no one knew what it was. It was labelled 'Fever of Unknown Origin'. Patients were almost entirely young men in their mid to late twenties who would come in unable to breathe, and they would get oxygen masks, and we would increase the oxygen, and then they would be dead, like in two weeks. ... There really weren't many at the beginning and they were really all young healthy

people who suddenly couldn't walk up a flight of stairs and became rapidly ill. They ended up on respirators in the intensive care unit, and then they died, because they really didn't realize what was going on. The bacteria, well, now they think it's a fungus, get into your lungs and make them fibrous so the oxygen can't get through; so no matter what they do for you, you can't get any air into your body. It was really something. They had terrible fevers which we couldn't control, because they weren't from anything we could treat with antibiotics, so they would get everything, and still nothing would work. It was pretty horrifying.

For Alice D., at the time in private practice in lower Manhattan, the appearance of HIV followed a decade of seeing an increase in venereal disease. Her patients were almost all gay, white men who lived in the Greenwich Village-Chelsea area. The sexual revolution of the 1960s and the development of homosexuality as a lifestyle created the conditions for an epidemic of sexually transmitted diseases (STDs). When HIV disease became apparent, it was through patients presenting puzzling symptoms. She said:

There was a lot of coming out of the closet, and there was a lot of celebration of the change in lifestyle, of people who had here-to-fore felt very much repressed and ashamed, and as a result of that we saw a lot of venereal disease, STDs as they are now called. That was throughout the 70s, and then in late 1980, we saw symptoms of a disease that we didn't know how to diagnose, we didn't know what was going on. I think our first patient had, in retrospect, PCP, and of course people get

pneumonia all the time, that's nothing uncommon. But this was a particular type of pneumonia that you just don't see in people who are not immunocompromised for some other reason. I think our next patient had KS, and again you look it up in the medical books, and here-to-fore that had been a disease of mainly elderly men of Mediterranean origin. Young people weren't supposed to get it. All of a sudden we were seeing all these patients whom we had seen on a very regular basis, treating their gonorrhea and their hepatitis and their giardia and other diseases which I had not heard of before I came to work in this practice; all of a sudden they were coming in with unusual symptoms, they were losing weight, and their blood counts were falling.

These patients with mysterious ailments, with gastro-intestinal disorders and respiratory difficulties for which nothing worked, linger in these nurses' memories. They were the vanguard of the present epidemic. But it was not apparent at the beginning how serious the disease might be or how many might be involved. These were just individuals who had something which didn't respond to treatment. There was no suggestion that treatment might not be available. Marcia B., who was working at the time in a Manhattan emergency room in the East Village, described what she considers her first HIV infected patient:

One weekday evening, I was in the ER, he came in with diarrhea; he was a German immigrant, a frightened little rabbit with incredible blue eyes, and since we didn't know what was causing the diarrhea, we thought it might be Crohn's

disease, we put him on hepatitis precautions. He was in for a couple of weeks, and I think the staff really mothered him. His English wasn't too good, he didn't communicate that well, and he looked frightened all the time. This huge black man who was his pimp came in and we became very protective of -----. He was worked up and he was discharged with a steroid for Crohn's disease, and I guess he was out for about two months and he came back in, and he was on the floor for about three months, just getting sicker and sicker. Every specialist down there came in to see him. Finally we transferred him to the ICU [Intensive Care Unit]; he was just deteriorating awfully. No one could figure out what was wrong with him; he was in the medical ICU for three weeks before he died, and then we got the autopsy. It showed his whole body was invaded with herpes. The colon was perfect.

The frustration for the nurse of trying to deal with something that resisted treatment was matched by the frustration of the patient for whom no treatment worked. Roberta S., who was just at the beginning of her nursing career in 1981, remembers how difficult it was for the patient, not knowing what was making him ill:

We had this patient, he was black, and he was a drug addict, and that was something I don't think he knew we knew. I just remember him being so frustrated himself at no one being able to figure out what was wrong with him. They had run every test imaginable, and his temp would go way up, that was fascinating , but we couldn't find anything wrong. He didn't look like a person who was infected. A lot of people

when they're infected, they're kind of lethargic and lying in bed, and they know where they hurt. The blood count's real high, and you give them an antibiotic, and then they get well. That's an infection. But this guy had all these high fevers, and he wasn't showing the picture of infection. I don't remember what his blood counts were, but I do remember how sick he was, he couldn't get well, and he was so frustrated. Every day I would come in and hope that yesterday's test had found something, and I remember getting frustrated myself, and feeling his frustration, until the day I came in and that was it. He died. He died trying to find out what was wrong with him. They couldn't find what in the world was the matter with him. He just kept getting skinnier and skinnier and skinnier and he never got well, and we'd given him everything in the world. He couldn't hold any food down either, and he had all that diarrhea.

The recognition that this was a new disease is forever associated for Alice D. with the weekend of July 4th, 1981. She said: It wasn't until July 4th, 1981 as a matter of fact, I remember that weekend because I happened to be visiting friends in the country, and I was telling them about this strange new cancer that we were seeing in gay men, and they started rolling their eyes around and saying "you're making this up," and then it came out in the New York Times, and it was the first time it hit the mass media that something was going on.

But having a name and the recognition of a new disease, when treatment did little to help, was a dubious advance. Now patients

had an identifiable condition, but the reality was that they continued to suffer and to suffer without much hope of relief.

That first HIV patient made a strong impression on these nurses. For Frances L., who was no older than these patients, her first HIV patient "was a young guy who was a dancer. He had Kaposi's sarcoma [KS], where they get the big purple patches. I remember him so well, he had them in his rectum, it was just terrible, because I remember he had these beautiful long legs, and I just remember him lying in bed in pain."

The numbers of these patients grew inexorably, from 143 reported in 1981 to a peak of 6800+ in both 1988 and 1989. It was no longer an isolated patient here or there who baffled medical diagnosis. It became quite quickly, over the course of four years when reported cases moved from low three to high four digit numbers, a group of patients whose medical and social characteristics required extraordinary response.

HIV disease is not a kind infection. As Carol H., a nurse with more than twenty five years of experience, said: "I think the thing that I found about HIV disease, more than cancer or anything else, is that it's the nastiest disease. It seems to affect everything, and it's so degrading to have it. You're not allowed any dignity, and certain people, like gay people, who are very tied up with their appearance, it can be awful because many of them have KS [Kaposi's sarcoma], but even if they don't, it's not a pretty disease."

It is a disease which frequently leaves the patient with little dignity at the very end. They become totally dependent on their caregivers for the basic routines of life. It is one aspect of the

disease which evokes strong feelings of pity and horror and anger. Meeting that first patient in the end stages can be a searing experience. Asked to describe her first encounter with an HIV infected patient in the hospital, Lena F. said her first encounter was in 1986, shortly after she graduated from nursing school:

He was young, 25, and I was really new on the floor and he tried so hard to help himself. He had such horrible edema, his scrotum was so enlarged that he actually had to hold it when he got out of bed, and every day he would just get bigger and bigger, just filling up with fluids, and having massive diarrhea, and really having a very, very hard time. But he was quite alert and was conscious of everything; he was aware. I'll never forget this, one day I was with him, and he was so bloated and having such terrible diarrhea, and he wanted to go to the commode. I got the commode, and he got up, and there was an explosion. It was all over everything: him, me, the floor. He was so big, and he put himself down on the bed, and he said, "I'm sorry." I was so angry at the disease. I was just so angry. It was just such a damned, horrible thing for this poor guy.

Since those early days, HIV infected patients have become anything but a rarity, and some of the shock of the manifestations of the disease has worn off for those involved in their care. But the pity remains. As Bob G., a clinic nurse in a hospital with a largely immigrant, young group of HIV patients said, "They're young, they look like us, they don't seem any different, but they don't have much time. That's what really gets you." It is pity for the beautiful young

Hispanic woman on her first visit to the HIV clinic. It is pity for the IV drug user who never thought he was going to live very long anyway. It is pity for the women who will never see their children as adults and the children who die before they know what life is about. It is pity for those who lose their lovers to HIV disease and then wait to join them. HIV infection can be a merciless disease. Against it the nurse's weapons can seem puny indeed.

VIII Choosing HIV Care

Compassion for the suffering of people infected with HIV and a desire to help are the first reasons most of these nurses, (72% of those interviewed and 69% of those surveyed), gave for their decision to become involved in the care of HIV patients. The desire to help sometimes springs from family background. Jean C., a homecare nurse, attributed her commitment to the training her parents gave her:

My family is all in social services. My father is a policeman, my brother is a district office manager for a child welfare agency, my parents are very socially conscious, so I guess there's a strain of service there. I think there probably was. I'm not so sure I would ever have chosen accounting even if I had been given the opportunity: it just wasn't the way I was enculturated. My parents taught us that people were important, and that I needed to think of them as well as myself, and even sometimes before myself. I think that probably made a difference.

The push to become involved felt like a compulsion to some nurses. Abby G. said: "When I'm in the middle of it, it's almost I feel I have to do it. And while I complain a lot about it, I don't know that I could do anything different." Carey M. agreed. She sought out her present position when she finished her MPH [Master's in Public Health] degree. She said:

People say, "How can you work there?" and I say, "How can I have the education and the knowledge that I have, and the experience that I have, and not bring it to this horrendous

epidemic which is going on here?" I couldn't think of not doing it. I have experience in maternal health [she worked in a HIV prenatal clinic], I have experience in addictions, and I have my master's in public health. I'm a perfect set up for it, and I couldn't not do it. I couldn't not do it.

Some nurses feel a close connection to the patients they care for; 14% of those interviewed and 19% of the nurses surveyed felt an identification with their patients. Gladys P., a black nurse in a city hospital, said simply: "These are my people. It's my community. I want to take care of them."

The community may be a racial, ethnic or sexual group. For homosexuals, the appearance of the epidemic in the gay community lay behind some decisions to go into health care. One male nurse said his decision to go to nursing school coincided with the appearance of HIV disease, and he went through his training with the goal of finding a job in HIV care as soon as he graduated. A lesbian nurse said her involvement was due to her desire to help the gay community. Arthur R., another gay nurse, said he became interested in HIV disease when he worked in an emergency room and saw how the gay patients were treated. He said:

I always felt a special bond to anyone who came in in a dress who happened to be a male, and years ago, maybe five years ago, when this thing about AIDS was coming out, no one would go near them. But I would go near them, and I felt responsible for them and an affinity to them, and I thought it could be me. I made sure they got a good deal. If their bed needed changing, I changed their bed and all that stuff.

Other nurses (66% of those interviewed) ascribed their involvement to their ongoing commitment to providing health care, particularly to those groups not ordinarily well served by the healthcare system. Sixty four percent (64%) of those surveyed concurred. One nurse in an 'elite' hospital said she had always nursed on the margins, in prisons and with TB patients. Now it was HIV disease. Paula T., at a city hospital, said the same thing:

I've always worked in areas that have not been fashionable as far as nursing goes. I've worked with drug addicts, battered women, and in areas that usually people find taxing, but I've always felt that people who need the health care most are often the ones who don't get it, so I've always gravitated towards areas that people aren't clamoring to work in.

This same nurse saw herself in her patients although, on almost any kind of social scale, she would seem to have little in common with them. Her patient population is predominantly minority IVDUs [IV drug users]. But, as she said:

I'm a child of the sixties, and I experimented with a lot of chemicals when I was in college, so I have a slightly different perspective on what drug abuse is. For me it was a period of experimentation, but there were certainly enough of my peers who got lost in the whole drug experimentation period. It became a very fine line for me between who can experiment and leave it and who can't. When I began to see it as such, I really began to see it as just something that people get involved in because of who they are, and if they wind up losing their life to it, which I think a lot of people have actually

done, it's only probably because they have no control over it, physically or emotionally. My feeling has always been, and maybe that's the way I grew up, but it could be me there, it could be someone I care about, it could be someone that I'm intimately involved with.

A significant number (26%) of these nurses, and 23% of those surveyed, have encountered HIV disease in their own lives. This is another motivating factor in their decision to care for HIV infected patients. Some have lost friends and family members to the disease. Lore H. feared for her brother and decided to learn as much as she could about the disease:

AIDS has hit me both on a professional level and on a personal level. I have a brother who is HIV infected. I had a feeling, since the statistics were that about 75% of gay men were infected, somehow I knew that, sooner or later, I felt that my brother was at high risk, and that he was going to come up positive, so that's what actually got me very interested in the disease.

Abby G. cared for a friend's husband and was drawn into HIV care through that experience:

I was taking care of a good friend's husband who died at home, of AIDS, not on any other basis than that he was a friend of mine, and I just really got involved in treatments and the devastation it really wreaks on a family. It's just something that I figured I just had a tolerance for dealing with those kinds of things; I don't know where it comes from, but I do. I always felt that there I would be most useful. And so that's

just sort of how I fell into it. And since I have a background with drug abusers, and because a large number of people with AIDS now are drug abusers, that helps as well. It sort of seemed like a natural progression.

Not all the nurses in this study have had personal brushes with HIV disease, however, and for some, their involvement comes not from personal identification with the patient or the disease, but from their professional training. They are nurses and as nurses are there to take care of patients. Marcia B. dates her commitment to HIV care from the early days of the epidemic when patients were openly shunned and isolated. This seemed wrong. As she said:

I remember one patient, who was an artist, and it was still at the point where everyone was wearing space suits to go into rooms, I loved to go to see _____, because when the place was crazy outside, I could go into his room and sit down and watch him paint. I developed a rapport that way, plus I guess it was the advocacy role that made me more involved because of this incredible fear that was going on, from the housekeepers and nurses and doctors and everybody else. Because back then, patients would say, "why do people come in dressed like that, the gowns, the masks, the gloves?" I had some housekeepers who put on hats and booties just to walk in the door, not to go near the patient, just to mop or to empty the garbage, and they wouldn't speak to patients. They probably wouldn't even look; but early on, I had two or three patients who were there two or three months, and who repeated, and I developed relationships with them, so they became very important, the

same as any patient I had for three or four months, and I resented it when people upset them. So it was an advocacy role, I think that's how the interest developed. That goes back to my undergraduate education. I was taught from day one you are the patient's advocate.

Emma J., a nurse clinician at a suburban hospital, was similarly propelled into HIV care when she discovered that many of her colleagues felt justified in refusing to care for HIV infected patients. As she described her path to HIV care:

When I first started reading about AIDS, I was interested. Something drew me. I wanted to know what was going on. I was working at a blood service at the time, and I missed bedside nursing. I loved bedside nursing, but I took the blood job because it was a day job. I had been working nights, and I couldn't do that any more [it was too tiring]. But I always missed the hospital, and I started reading about AIDS, and I started reading about nurses and doctors who wouldn't take care of these patients. I couldn't understand it at all. And a nurse I know told me about the refresher course for nurses she was taking, and how they spent a day on HIV, what it entails and all that sort of thing, psychological aspects and whatever, and the students in the course were asked to go home and talk to their families about it and come back the next day and tell the instructor how they felt about taking care of AIDS patients. So they all came back and said, "No way, never." I was infuriated. Absolutely infuriated. I said, "OK, that's it. Put your money where your mouth is." So I went to a seminar

and then started working at ____.

Sometimes the appeal of this work comes from the opportunity to set up something new, to be in at the start and establish a program to take care of HIV infected patients. Eight percent (8%) of the nurses interviewed and 10% of those surveyed were attracted by the chance to be in at the beginning of a program. Because HIV disease prompts such strong negative reactions from many health professionals, some hospitals have opted for dedicated AIDS units where all the patients have been definitively diagnosed as HIV infected. For those able and interested in taking care of HIV infected patients, these units offer good opportunities. Gladys R. said that this was part of what drew her to HIV care, much as it had drawn her to other areas of nursing:

As long as I've been working now, about 30 years, I like to work where there's something new, where there's a challenge. When they first started dialysis, I opened the dialysis unit, and when I came here, they started IV therapy, and now I'm head of the IV therapy in the AIDS unit. Where there is somewhere where I can make a start, a start from the bottom up, and see it grow, that's a challenge. I like a challenge like that. About five or six years down the road, it becomes little bit too commonplace, and you're just there, nothing to really challenge you, and I'm ready to go.

Part of what also attracted this nurse was the chance to do it right. She had been upset when nurses in other units of the hospital wanted no part of HIV care. She said that, by joining the new unit, dedicated to HIV infected patients,

we were going to let the patients know that we weren't afraid of them, so we only wore gloves when we had to do things with their blood, and their feces and urine and things like that. Otherwise, with patient contact we didn't wear gowns and gloves or masks. We wore masks only if it was a respiratory isolation, or we wore gloves if making skin contact and if they had sores or wounds or things like that. This was the first time this was being done, because in other places they had to put on the gowns and masks and boots. They would take the tray and slide it in the room. This [unit] was going to be a pilot. We touched the patient and rubbed their backs and things like that. This was the way we opened up.

Commitment to HIV care thus comes from a number of directions, from personal values, from professional training, from identification with the patient. It can also flow from an intellectual interest in the disease itself. Forty eight percent (48%) of nurses interviewed and 51% of those surveyed mentioned the attraction of a new and baffling disease. HIV disease is intriguing. It has myriad manifestations. As Alicia P., a staff nurse in a voluntary hospital, said:

You never know what system is going to be affected. For example, if you had someone with leukemia, you know where you'd have to look, like if their platelet count is very low, you don't want to give them intramuscular injections. So you know what to assess and what to look for. But in this, every organ system is involved, their skin, their nervous system, orthopedic problems, their lungs, their heart, eye infections.

So it's every organ system you have to monitor. In order to provide the care needed, a nurse has to keep on top of developments and keep abreast of what's happening. Alicia went on to say:

You really have to be on top of the things you have to know. A drug may give them seizures. When we gave pentamidine in the early days, instead of inhaling it we used to give it intravenously, and it would make their blood sugar go way down, and they'd get hypoglycemic. It's the whole gamut. You're not just dealing with a forty year old guy who had a heart attack. You're dealing with a lot of complex issues.

This is also part of what makes HIV care attractive. It is an opportunity to be involved in something new and challenging which demands concentration and attention. Twelve percent (12%) of nurses interviewed and 5% of those surveyed were looking for a change. Gloria R., a midwife who has practiced for twenty years and whose position before her present one in an HIV prenatal clinic was in developing programs to prevent premature births, attributed part of her interest in HIV care to the challenge of bringing HIV infected women to term and through delivery. She said:

I like doing high risk pregnancy. I mean I never would have thought a few years back that I would be doing this or doing the prevention of prematurity. I loved doing prenatal and the deliveries, but I also like the challenge of high risk. I liked the women I was taking care of in the prematurity study who had had previous stillborns or second trimester losses; there was intense followup with those women, and I liked that. I

would never say that pregnancy and delivery is boring because it isn't, but this is a little bit more challenging to me, and I like that. I like that.

Part of the appeal can be the pleasure of working with dynamic and caring colleagues. Twenty percent (20%) of those interviewed and 48% of the nurses in the survey said one of the satisfactions of HIV care was working with like-minded colleagues. Gloria described her switch to HIV care as serendipity:

The project manager [for this study] came to our local chapter meeting to talk about this program she was setting up and said that they were looking for nurses. So I'm sitting in this meeting and I said, "I like this woman." She's about my age, very laid back, and I could see she was honest and caring. So I said, "Give me your card and I'll call you tomorrow." So we talked on the telephone and we set up an appointment and it was just like love at first sight. I knew that I wanted to work with this woman because I could see that she was really into it and dedicated to it. She wasn't doing it because it was a job, in fact all the people in the program, the people who work here choose to work here because they're interested to work here and they want to help, and I got the sense that they were caring and it wasn't just a study. They got the grant and they worked it all out but they weren't just doing it because "oh yeah, here's a grant, we'll do a grant," but their heart is in it.

This is one of the reasons many nurses prefer to work in all HIV units. A special inpatient or outpatient unit for HIV infected patients or a residential facility for long term care of AIDS patients

offers the nurse the support of like-minded colleagues. This is particularly important in HIV care, because the disease and the patients it infects inspire fear and avoidance among health personnel. Forty six percent (46%) of the nurses interviewed and those in the survey said that they were stigmatized because they cared for HIV infected patients. It can be difficult to maintain one's convictions when colleagues think otherwise. As Peter Berger comments, "Most of what we "know" we have taken on the authority of others, and it is only as others continue to confirm this "knowledge" that it continues to be plausible to us" (1990 [1969]:7).

Nurses in HIV care need confirmation that they are doing the right thing, that these patients have a right to care, and that nursing intervention can mitigate the terrors of the disease. Nurses in HIV care can suffer a kind of siege mentality, because the stigma of the disease and the fear it engenders, even for those who have chosen to do this kind of nursing, can cut them off from their friends, family and colleagues. A dedicated HIV unit can provide cognitive and emotional support and encouragement. Working in a group committed to HIV care eliminates some of the stress of continually having to justify either to oneself or one's coworkers the correctness of one's behavior. As Robin M. said:

In general what I like is the motivation of the other health care workers in AIDS. I work with people who have also chosen to work with AIDS, and if you go to other units, you have AIDS patients there and nurses, doctors and anyone who takes care of them have not really chosen to work with it. Sometimes I see reluctance, and sometimes I even see

hostility, towards me or towards the patient which is worse, even if it's latent. They won't say, "Well, I hate you because you use drugs, but there is that little undertone that I sense. And here I come in and I feel like I'm coming home. Here we really look out for the patients. We'll say, "Oh, I went into Joe's room and he's doing so much better and I brought him some chili. He likes chili. Or I'm going out to Wendy's, what should I bring Mary?" We buy for the patients. We pay for the TV. It's a crowd who wants to work here, and that's very important. I like to associate with the group that's interested in AIDS care.

It is also true that for some of these nurses HIV care has given them professional opportunities otherwise not often available in nursing. Twenty eight percent (28%) of nurses interviewed and 19% of those surveyed cited the job itself as an inducement to specialize in HIV care. Along with commitment to care and concern for the patient as well as interest in the disease, there comes a realization that HIV offers some nurses the kinds of jobs they have been searching for. In the United States, nursing has always felt hampered by its beginnings first as a domestic responsibility of women and then as an adjunct to scientific medicine (Reverby 1987; Melosh 1982). Professional nursing is still seeking a way to stand alone.

HIV disease is offering some nurses the opportunity to practice autonomously. 69% of those surveyed said that HIV had increased their autonomy and 67% said they experienced improved collaboration and collegiality with physicians. One survey respondent said she was given more autonomy than she wanted. Because doctors

are not flocking to take care of AIDS patients, some institutions are turning to nurses to provide primary health care. In one hospital, the HIV unit is under the daily supervision of a nurse practitioner, not a doctor. Another of the nurse practitioners in my sample accepted a fellowship in primary HIV care offered by a leading voluntary hospital. These positions have a great deal of responsibility. As Carol H. described her position in a residential facility:

It's really the best job I've ever had. I like the autonomy. I like very much not being part of a structured [work setting]. I never liked working in a hospital. I did inpatient on the floor for only about six months, and that was right after I graduated from nursing school, and the rest of the time it's been public health nursing or working as a nurse practitioner in a health clinic. I put in more than the number of hours required, but nobody checks on them, and it's just very gratifying. I'm pretty much on call 24 hours a day, but that's OK.

Lena F., whose colleagues pointed out to her that without HIV she wouldn't have her job, replied that she didn't want anyone to be sick, she didn't want to see anyone suffer, but at the same time, she said:

This is one of the most gratifying jobs I could have as a nurse, because I feel I'm using every skill that I have, that I've been taught, that I've acquired over the years. I really think I'm doing as much as I can, I'm working to capacity. I'm really able to give, I'm not just going in and saying, "Well, I have three baths to give, and I have to give out 20 meds, and the patient doesn't want to hear what meds." Here the patients really

listen to me, they give me respect, they listen, they value my opinions. It's a very interactive process.

The desire to use their skills and talents to the fullest is one of the reasons many (56%) of these nurses and 58% of those surveyed cited for their decision to become involved in HIV care. They are proud of what they can do for patients. Caring for HIV infected patients enables many of them to do all the things they ever wanted to do that they were told good nurses did, but which they never had time to do before.

One of the reasons this is possible is that for those who work on an HIV unit the ratio of patients to nurse is usually lower than on regular units. Thus nurses have more time per patient. One municipal hospital opened its HIV unit with ten patients and five nurses. It has since failed to maintain that ratio, but it is still far better than the ratio on other units where, in this particular hospital, there can be one registered nurse for forty patients during the day and none at night. Most AIDS units have between five and eight patients per nurse. This desirable nurse-patient ratio has been used as a recruiting inducement by some HIV units, but it alone cannot attract nurses. In the municipal hospital mentioned above, it is still difficult to attract nurses to the dedicated unit, even though nurses on the regular wards may be caring for as many or more HIV infected patients already.

If working conditions alone determined nurses' decisions, dedicated HIV units would be flooded with applicants. Some units do have waiting lists of nurses eager to sign on, but these are very well run units with a demonstrable esprit de corps. Not all HIV units

work well, even when staffed with nurses committed to HIV infected patients. The human mix is always an important factor.

This is why none of these nurses cited just one reason for becoming involved with HIV care. Most mentioned the desire to help first, but with all of them, there were also issues of personal development and professional growth. There is no one profile which fits these nurses. Some find being by the bedside the place they want to be; others can't get away from it fast enough. Some like hospitals; some prefer home care. Some focus on managing the symptoms of the disease; some are more interested in the psychosocial aspects. Some gravitate towards taking care of women and children; some others prefer IV drug users; others find homosexual patients the most satisfying they have ever had. The variety of the manifestations of this disease offers nurses a number of different ways of being involved. There are different practice settings, different patient populations, different infections. Each has its particular challenges and satisfactions.

The different groups who are infected with HIV, the different infections and conditions they suffer, the different setting within which care is given, make it possible for these nurses who want to care for HIV infected patients to be involved with the kinds of patients they feel most drawn to in the setting which they feel most comfortable in. Those who work best with highly educated and motivated middle class patients are able to work with them. Those who find the greatest satisfaction working with groups on the margins of society or those actively rejected by society have no trouble finding them. Nurses who want to care for gays or for

women and children or for blacks or Latinos are sure to locate opportunities.

Nurses who like the support of institutional structures gravitate towards hospital work. Nurses who like to be on their own, perhaps more intimately involved with patients in informal settings, will choose homecare. Nurses who like research can find positions in clinical trials. Nurses who want direct patient contact can find it in different intensities in hospitals and clinics and home care. Nurses who want a more distant role also find a number of positions in administration or teaching. Just as there is no one model of HIV disease, so there is no one model of HIV nursing.

Until very recently the nursing shortage coupled with increasing demand for nursing care gave nurses in New York City unparalleled opportunities for finding personally satisfying jobs. When I started my research in 1989, an administrator told me that the demand was so great that any nurse at a municipal hospital could walk out and get a job at a more prestigious institution. And indeed as the "elite" hospitals opened HIV units in the late 80s, they often recruited nurses who had experience with HIV from city hospitals.

Because of the nurse shortage, salaries for nurses increased substantially in the late 80s to the point where staff nurses with 20+ years of experience can command \$60,000 - \$70,000 in elite hospitals, with substantial additions from overtime. It is not unknown for a head nurse to make close to \$100,000. New graduates in voluntary hospitals now start with a base salary of \$40,000 with differentials for night duty and/or specialty positions. Municipal hospitals pay less by about 10%. Positions beyond the

staff nurse level pay higher salaries in all hospitals, and there is an additional increment for advanced degrees. These numbers are, of course, gratifying to a profession which has been traditionally underpaid, but the nurses in this study were working and continued to work when salaries were much lower. In 1987, one of the sample, a nurse with a master's degree, accepted a staff position in a voluntary hospital at a salary of \$26,000. Another said her salary in 1983, as a staff nurse in a dedicated unit in a municipal hospital, was \$23,000.

The nurses I interviewed took advantage of the demand for nurses to find the jobs they wanted. This is one very attractive aspect of the profession of nursing, that nurses can change positions quite easily. Among the nurses in the Association of Nurses in AIDS Care there is a continual sharing of information about jobs and opportunities. In order to take advantage of these opportunities nurses have to keep current, sometimes they have to take a refresher course, and they have to take the initiative. But there are so many different kinds of positions for nurses that savvy practitioners have a luxury of choice unknown to many other professionals.

The arrival of HIV disease in the 1980s opened up a number of nurse positions in the New York City health care system. At a time when hospital beds, system wide, were being eliminated, HIV disease was a growth sector in the medical industry. New units were opened, new clinics, new home care agencies. Each of these offered nurses the chance to move if they were willing to develop an expertise in HIV disease.

Comparison of Interview and Survey Responses

Table 1

Question #1: What prompted you to become involved in HIV care?

Response:		N	%
1. desire to help	interview	3 6	72 %
	survey	3 9	69 %
2. desire to use skills/talents	interview	2 8	56 %
	survey	3 3	58 %
3. intrigued with disease	interview	2 4	48 %
	survey	2 9	51 %
4. personal contact with disease	interview	1 3	26 %
	survey	1 3	23 %
5. attractive job	interview	1 4	28 %
	survey	1 1	19 %
6. AIDS unit opened	interview	4	8%
	survey	1 0	10 %
7. commitment to community	interview	3	6%
	survey	3	5%
8. wanted change	interview	6	12 %
	survey	3	5%

IX The Challenges of HIV Care

When the trickle of patients with HIV disease turned into a stream and then a torrent, it became apparent that the incidence of the disease varied geographically and demographically. The first group to be significantly threatened was that of young, white gay men in cities where the homosexual lifestyle had become established in the 1970s. New York and San Francisco were hardest hit, and until very recently, the number of gay PWAs (person with AIDS) has outpaced all other categories of patients.

The second group to be affected was that of intravenous drug users (IVDUs). Again they tended to cluster in large cities where drug use was endemic. Numbers of young black and Hispanic men and women, some of whom were also gay, began to appear in hospital units, clinics, and as patients to homecare agencies. The third group, currently the fastest growing but numerically still far fewer than gay men or IVDUs, is that of women and children. Women contract HIV disease most often through their own drug use; the second largest number become HIV infected because their sex partner is infected. There are also, of course, patients who have HIV disease but who do not fit these categories, but their numbers are very low.

From several points of view, gay and IVDU PWAs have from the first been unsettling to those who have been expected to care for them. Until HIV disease brought gay men into the hospitals and clinics, they often remained in cultural ghettos (Gorman 1986). IVDUs, according to my informants, sought care in emergencies but otherwise neglected their health. Then, quite suddenly, over the

course of a few years, beginning in 1981, large numbers of these patients came for care.

Many of the nurses in this study were not familiar with these kinds of patients at the start of the 1980's, and in order to understand the special characteristics of such patients, they called on their professional commitments and their personal skills. Their professional training said that these people were something other than the sum of their social characteristics; when they came for care, they were 'patients'.

Patients are people in distress, in need of care, care which a nurse knows how to provide. The category of 'patient' enables the nurse to leave aside the particularities which social labels such as gay or IVUDU suggest, and to focus instead on the individual as a person in need of care. The person's particularities have an impact on care, they must be taken into account, but they ought not, in this construction, disturb the basic posture of nurse and patient. The nurse proffers help, and the patient accepts it.

Yet the generalizing and abstracting effect of the concept of 'patient' has to mesh with an understanding of social characteristics if care is going to be appropriate to the individual. It is here that nurses begin to use the skills of social science and of anthropological fieldwork, in order to bridge the gap between themselves and their patients so that proper care can be provided.

The essence of these nurses' approach to their patients, similar to that taken by anthropological fieldworkers, is acceptance of the 'other'. Ideally, they do not judge; they seek to understand. Although their own personal convictions and code of behavior might be very

different from their patients', such differences are not allowed to interfere with the process of understanding. Off-duty, much as anthropologists have sometimes confided their private opinions to their diaries, these nurses might be critical or despairing of their patients. But on-duty, their mental attitude is one of receptivity and acceptance.

Some nurses contrasted their own attitudes with those of their colleagues who had difficulty caring for gay men or IVDUs. They told me of older nurses, and those trained in other countries, who were sometimes totally unprepared for the kinds of patients they were asked to care for. Nina H., a young nurse in a municipal hospital commented:

You have some nurses, they're older, and to ask a 55 year old woman to deal with this transsexual, who's a cross dresser, for example, is a lot. We've had some real blatant queens, the ones who have already had the breast implants and stuff, and some of the nurses here are really shocked.

Some of the nurses who have trouble caring for PWAs are uncomfortable because they disapprove on moral grounds of the patient's behavior; others are simply embarrassed to bring up sexuality and/or drug abuse, even though knowing whether the patient engages in these activities is important in planning his care. Whole areas of life which used to be matters of only private concern are being brought out into the open with HIV disease.

In addition, even for nurses who have worked for years in the municipal system, the HIV infected population can be distressing because so many are so very poor and so very needy in so many

different ways. There have always been service patients in both public and voluntary hospitals, patients whose care is paid for with public funds. But even in city hospitals these patients were interspersed among middle class and working class patients. With HIV disease, the patient population is becoming increasingly poor and marginal, those without much of a toehold in mainstream America. This can be upsetting to nurses who, through their profession, have achieved middle class standing, and who value middle class standards. This change in patient population also makes nursing more challenging; teaching and counseling about good health habits and medication schedules have to be geared to the patient's capacities. Nurses caring for HIV infected patients cannot assume that their patients lead well-regulated lives and that they possess the skills needed to comply with complex medical regimens.

Some of the nurses I interviewed said they had to work at developing the openness they needed. Even nurses fully committed to HIV care can be uncomfortable talking about sexuality and/or drug use. It is not unusual for patients to ask nurses about the safety of oral and anal sex. Suzette J., in charge of education at a city hospital, grew up in a very liberal European country, but even she had to learn a lot before she felt comfortable dealing with certain subjects. As she said:

I don't have a problem talking about sex; I don't have a problem now, although I used to. I don't have a problem talking about needles. I used to, but I learned not to, because otherwise I might as well sit behind my desk and not get up, because we're not going to change anything if we

don't know it, or when we ourselves are uncomfortable talking about it. Many, many people are, and some of the patients look at me surprised, because here she comes in this middle class way, she talks about shooting up, and uses terms we use on the streets, and she sits there, and she says these things and talks about that sort of thing. I think it helps.

In her use of intellectual knowledge as a method for overcoming personal discomfort, this nurse is using the same technique and approach which a fieldworker might in trying to understand another social group. Knowledge can be an antidote to fear. Nina H., who worked in the same hospital as Suzette, agreed:

I feel that anyone who works in HIV should have at least one course in sexuality. If you're not comfortable saying the words or the terms, there is no way you can counsel somebody. I've had discussions with people about whether blow jobs can transmit it, and sometimes they don't know how to say it, and I'll have to say, 'going down' or 'blow job'. So you have to be comfortable hearing it and saying it.

Central to the acceptance the nurses in this study practice is the ability to put their own preferences and beliefs aside. Much as anthropologists try to blend in with the people they study, nurses do not bring their own code into the workplace. Several said that they heard many things which shocked them and many things which they would rather not have known. As Nina H. went on to say:

I heard one woman explaining how she gave blow jobs to pay her rent. I can't judge her, but it's not what I would like to do, and I really felt like telling her, "Don't you feel like you're

being used?" But it was an uncomfortable situation for her, and I wasn't going to make it worse.

It can work the other way, too, when nurses' attitudes are more liberal than their patients'. Marcia B., working in a municipal hospital where every kind of ethnic and racial group was represented, said of one of her patients:

I had a patient who was Muslim, and the idea of his homosexuality, he felt he was being punished by God. So you had to be careful talking around that. It wasn't a matter of not saying anything. You had to appreciate that someone like him, you almost let him denigrate himself. He had to say [it]. He understood that it was the virus, but he took it as punishment, and at this point I'm not going to make him comfortable about his homosexuality. There's no way he's going to change his thinking. It's not for me to become a sex therapist.

The ability to distinguish between what one would do oneself and what one's patients do is critical to providing good care. It is also central to the anthropological enterprise. Instead of one's own values, others' standards come into play. In such a situation, the nurse tries to think and feel as the patient might think and feel. This is "negative capability." It is entering the other's world in order to make contact with them. To do this, the nurse must understand the patient's 'culture', the thoughts, habits, practices, prejudices, pleasures and pains which the patient takes for granted but which the nurse may not. As Cassie N., a staff nurse in a voluntary hospital where most of the patients were gay, explained:

On the average floor you might get a little uncomfortable with

a husband getting into bed with his wife during her hospitalization. Well, here, you deal with that but it might be two males. And as long as they're not disturbing a roommate, or doing something flagrant, or doing something that's going to make them worse, there isn't any reason why people shouldn't show affection. You just have to learn to get past that strange feeling. Some people get over it very quickly. Some people it takes a while.

Accepting the patient as he is is the first step in the process of discovery for these nurses; the next is using what they discover to reach and teach the patient. These nurses, for example, have learned how to phrase questions properly to get the information they need. Many of their IVDU patients come from Central and South America, so the nurse has to become literate in cultural concepts not perhaps her own. This means, among other things, knowing how sex is conceptualized in other ethnic groups. Marcia B. noted that Hispanic men do not think about sex between men in the same way that Americans do. She said:

Very often South American men, all the different countries, they don't think of themselves as homosexual. And if you ask them, they'll say, "No." But if you say, "Have you had sex with a man?" they'll say, "Yes." But you can't say, "Are you gay?" "Are you a homosexual?" They'll say, "No." Also the women, a lot of times, will not want to tell on the male, so they'll deny all risk factors. I still think of one woman, up to the day she died, she denied. And you knew the husband was a shooter, you just knew.

Heterosexuality inevitably brings in questions of relations between men and women. These can operate very differently from the patterns of interaction preferred by these nurses. One nurse who was Hispanic herself and whose patients are Hispanic said that sex is not commonly talked about in the homes of her patients, and so trying to talk about safe sex, particularly with men, is a challenge. As she said of one patient, "He won't even look at me, he puts his head down, and I just keep talking, and leave the condoms, and hope that he's absorbing some of it." Like an anthropologist seeking information from an informant, the nurse has to find a way to make her meaning clear to her patient without criticizing his beliefs and values.

This nurse started postpartum classes for Hispanic women at her hospital where they could discuss birth control and other issues related to sexuality, but she said that her patients did not feel at risk. It is hard to convince people that they are in danger if they are feeling well. And the advice that condoms should be used can run counter to fiercely held beliefs about who decides what between men and women.

One patient who went home to suggest using condoms returned to the clinic with a black eye. The nurse who had made the recommendation felt responsible for her patient's injury. At the time I talked to her she was puzzling out how to change and tailor her educational program to her patient's situation. Her predicament was that the advice she was giving was medically accurate but socially disastrous. She was looking for a way to bring the two realms into alignment in such a way that one would support the other. She had

not found the solution at the time of our interview, but in her response one can see the contours of the kind of thinking which makes it possible for these nurses to create an intellectual construct of their patient's world. This nurse used what she learned to affect and improve medical care. As she said about the teenagers in her community:

There are adolescents in the community who don't like to use condoms, and they're sexually active. Also among the Hispanic community, they tend to use anal intercourse to preserve the virginity of the girl. For young girls, virginity is prized. When I learned this, I said, "Oh my God," because this increases her risk, and she may be a virgin, but she may have AIDS. She may not get pregnant but she may get AIDS. So when we do sexual counseling with these girls, when we do a sexual interview with them, and the doctor asks them, "Have you had intercourse?" She'll say, "No," because they mean vaginal intercourse. She'll say, "I'm a virgin." And the doctor doesn't go any further. So we have to tell doctors how to do a proper sexual history.

The nurses in this study tried to look without preconceptions and moral judgment at how their patients lived. This enabled them not only to understand their patients but to present their patients' concerns and values to others in a sympathetic manner. Nurses occupy a position where several worlds come together, and many of the nurses in this study felt responsible for changing the perceptions of those who were unable or reluctant to put themselves in the patient's place. Emily D., who moved from direct bedside care of HIV

infected patients to teaching licensed practical nurses in a homecare agency, said of her work:

We're constantly having to educate people about the person's sexual orientation as part of their life. I tell them "maybe you're uncomfortable asking that question but you have to, you have to know." I had one nurse say to me that the patient was all upset because his roommate just died, and I said, "Was it his roommate or his lover?" She was embarrassed to ask. And I said, "Look, there's a big difference between losing your roommate and losing your lover." So that kind of thing comes up. With IVDUs, a lot of the nurses don't want to deal with the issue, so they don't even ask if they're doing drugs any more. And I have to be constantly pointing out to them that not only do you have to worry about symptoms, but also, are they sharing needles? are they keeping their needles clean? are they sexually active? It's interesting how some people will put on their blinders and they'll focus on the disease and then they'll just ignore these things over here, all the social characteristics and the stuff that makes them uncomfortable.

"Not ignoring all that stuff" is what makes these nurses effective, because it may be exactly that which is what one needs to know to decide what to do for a patient. As Emily D. explained:

Say I go in, and I find a patient who's acting a little strange, whose mental status is a little off, and I'm trying to decide, "did he just get high or does he have a central nervous system infection?" I had this situation when I was doing homecare.

So I asked him, "Did you just shoot up, I got to know whether to call the doctor?" And he said, "Yeah". So I said, "What did you do?" In this case he had shot heroin and cocaine mixed together, which they call a speedball on the street, and his pulse was 150. I had just taken his pulse, and I had to say, "tell me what you did, because otherwise I have to get an ambulance because your pulse is 150."

As can be seen from this example, it is essential that the nurse knows the patient well, because every aspect of living can affect the progress of their disease. Getting to know the patient intimately, in greater depth and detail than a standard nursing history provides, is therefore an integral part of these nurses' jobs.

Many of the nurses in my sample who took care of white, gay men said these were the best patients they ever encountered. They found the process of getting to know them pleasurable. On average, at the beginning of the epidemic, they were highly educated, and many had strong support systems of lovers and friends. They frequently knew more than their nurses about their disease. They were on top of the latest information. As Tom R., who worked in an "elite" hospital where almost all the patients were gay and middle class, said:

I read everything I can get my hands on, and all of my patients bring me in articles. I tell them I don't have time to read the New York Times every day, so if there's anything in it, please cut it out, and they do. Mainly my patients are my main source of updating. They're the ones with the disease. They're

the ones doing the research and a lot of them do a lot of research and really keep up with the latest information. That's a change for medicine, and that's making nurses and doctors feel uncomfortable, when your patients come in asking about the newest treatment, and you've never heard about it. They send for all the literature, and they read it thoroughly, and they very often bring up these radical new things in meetings, and we discuss them, and pick them apart, and say what might be wrong with them, and why people don't need to jump on every bandwagon.

These gay patients often kept track of their medications and their infections. If they were hospitalized, they were able to tell their nurses just when they had their last bout of pneumonia, for example, and what treatment they had. This saves lots of time and work for the nurse. Thus, with many gay patients, it was easy for these nurses to establish a cooperative reciprocity.

They often met as friends, as people who had grown fond of each other and who enriched the other's life. One nurse was somewhat startled to realize that what she took for granted, taking care of the sick, was an exotic activity to one of her patients. It was a revelation to him that someone would do what she did five days a week, 50 weeks a year. Some of these patients, like some patients everywhere, became very special to their nurses. As Emily D. said of one such patient:

I had this one patient, an artist, his whole apartment was just filled with things. He was a graphic artist and designer. He designed posters and bathing suits and he just loved life.

He would, on his good days, he would steer the conversation into what else was happening, even though he couldn't go out anymore. But he always wanted to know, "well, what did you do last weekend? Have you gone to any movies? Have you gone to any plays?"

As the proportion of HIV infected patients who are white, gay men has dropped, the numbers of patients who are or were IVDUs [IV drug users] or the sexual partners of IVDUs has risen. These are very different patients from white, gay, middle class men. As Carol M., who worked at a hospice where most of the patients were IVDUs, explained:

Many nurses would rather work with a gay patient than with IVDUs, because a lot of the IVDUs, it's so hard to connect with them. One of the reasons they do drugs is because they don't trust easily, and they're very angry about feeling so alone. But rather than reaching out, they pull in, and they do drugs.

It is hard, in general, to establish a mutual, reciprocal, open and accessible relationship with IVDUs. As a group, they are poor, often homeless, and disconnected from society. The skills they have acquired in order to survive on the streets do not serve them well in the bureaucratic, middle class setting of a hospital or clinic. They can be abrasive and threatening as well as charming and cajoling. Either way they tend to believe that rules and regulations do not apply to them. In medicine and nursing, where there are detailed protocols and procedures, such an attitude breeds conflict.

But for nurses who can accept them as they are, without asking them to change beyond what they are capable of, IVDUs or substance

abusers can be a pleasure to work with. Carol M. said of them:

Substance abusers can be delightful people. As long as your expectations are realistic, as long as you don't anticipate major changes, they are what they are. They will try to be manipulative, and you can't let your feelings get hurt and all that, but otherwise they are delightful. They make you laugh. It's rewarding to work with them.

This is not to deny that IVDUs present real management problems. Their manipulative ways are legendary, and it takes a confident personality to deal with them. Everything can become a battle. Gladys R., whose unit, at the time I spoke with her, was filled with IVDUs, said of them:

One thing I want to say about the IVDUs, the street people. They live in the street, they have nothing, they have nobody. They come to the hospital, they want everything and everybody to give them their full attention. They'll say, "I asked for two pork chops. How come I only got one?" Or they'll say, "My bed hasn't been changed." They'll come in and they'll be filthy, and we'll say, "We can't work with you, you got to take a bath." Lord, they fight you tooth and nail to get in the tub. Then once they get in, you can't get them out. They're in the water, they don't want to come out. And we say, "Wait a minute, there's other people besides you. Wait your turn." And they come out and they tell you, "My room hasn't been cleaned yet, look at it, it's filthy." And they'll open up the air conditioner, and say, "Look at that, that's why I'm coughing, the air conditioner is filthy." I mean, give me a break! They come off

the street, living on the sidewalk, and now they want the Ritz!

Dealing with IVDUs takes strength of will. They will try to get what they want through charm, and if that fails, through intimidation. One nurse described patients who would stand silently in front of the nurse's desk for hours in an effort to extract additional pain medication, even though they were told to return to their rooms. Ethel G., who worked with Gladys, said:

Oh, they curse you out. They treat you like you are a maid, not their nurse, and you have to be extremely strict with them to set limits. You have to set limits because otherwise they will run right over you. They will steal your things, anyone's things, even the outpatients' things. They even steal the other patients' food that you just left on the desk. When you come back, it's gone. So it's hard on the nurses.

Drug use continues for many patients even in the hospital. Friends bring them supplies and the drug is commonly added to the IV bag. This happens in the very best voluntary hospitals as well as in city hospitals where close surveillance is not possible. In one hospital the situation got so lax that patients could leave the unit, buy drugs on the street, and then come back to their rooms. The nurse who described this to me said of this situation:

They swear up and down that they never went out of the building. They take their clothes and they put them behind the steps. They come back, they put on their pajamas, and they walk in like they've never been anywhere, they claim they haven't been. They've been in their room watching TV or something.

This is an extreme example, but in general IVDUs can be difficult patients, difficult in the sense that they do not reciprocate. The nurse may be ready to understand but, because the nursing process requires a response from the patient, only half of the equation is in place if the patient doesn't do his part. As the nurse quoted above said, "You want it to be 50-50. You're there to help and the patient is there to get well. Everybody should work together." This is not easy to achieve. Margaret T., the coordinator of several units for HIV infected patients, said of the IVDU population:

People just don't like them. They don't talk like we talk, they don't act like we act. They have no manners, they don't appreciate what's being done for them. They're obnoxious. They insult you, and they're demanding. I have times when I just stand and hold on because you can't give them the satisfaction of seeing you lose control, because then they have won, and it's all over. But then you can't say, "I'm not going to deal with you" and run away either.

Dealing successfully with drug addicts as patients means being able to tailor one's expectations to reality, being ready to meet them on their own ground and at their own level, and yet also continuing to work towards better health behavior.

Although this could be said of all nursing and all patients, HIV infected patients make unusual demands on nurses' personal skills and emotional fortitude. Eighty two percent (82%) of nurses interviewed and 85% of those surveyed said that coping with patients' emotional needs was their greatest challenge. Even middle class patients who had insurance and were not dependent on public

programs and who might, therefore, be expected to be relatively self-sufficient, looked to their nurses for support. As Fran L., whose patients were mostly white, gay men, said:

If they have HIV disease and it's progressed to full blown AIDS, and they're going downhill, a lot of their support system falls by the wayside. They don't have as many people as, say, a cancer patient or a Crohn's disease patient. They've lost some of their support system to AIDS also, so they come to rely on their home infusion and their home therapy caregivers to an unbelievable extent.

Most HIV infected patients are young, often in their twenties and thirties, often the same age as their caregivers, and so it is perhaps natural that they turn to them for comfort and understanding. This is particularly true if the caregiver and the patient share common orientations. As Jason R. commented:

Sometimes, because I'm gay also, if they are gay, there's some camaraderie. They feel they can trust you, I think. Sometimes with drug users, there's a particularly strong feeling that they need to feel some companionship with you. They get friendly, they need a lot of people to talk to. They have a hard time, and maybe they can't tell everything to the people in their lives, so they just like to talk to you [the nurse] about things.

Another nurse who practiced home care said of her patients:

You're supposed to be the mother they never had, the sister they never had. You're supposed to know all about the disease and how to deal with it. Most patients feel that

they can keep loading on to you, and you're going to be able to cope with all of it.

The most common emotions which the patient experiences and which the nurse must in some way respond to are sorrow and anger. There is sorrow because HIV disease is ultimately a terminal diagnosis. Death may be delayed and treatments developed in the last decade do put off death for some time, but ultimately HIV disease is fatal. This is the message that the diagnosis brings, and it is a message which the nurse has to contend while striving to care for the patient. As George T. said:

So you come toddling in as the nurse, all efficient, doing your thing, meaning absolutely nothing negative, you just want to get your job done so you can get your chart in and run out the door because you've got so much to do, and here's this person who has just been told that it's HIV, and to them it means death. They need a lot, even those who don't say it.

Some patients are more expressive than others and some groups seem more able to set up systems for coping than others.

Nora M. whose patients were poor, mostly IVDUs, had this to say:

With the drug users, they are not able to advocate for themselves in the same way. They are very very fearful, and they are not able to express their fears. You find that you have to advocate for them, it's very hard to reach them, it's hard to get their confidence or their trust. With gays, it's much easier. With the drug users it's much more difficult to get them to verbalize what's really going on, because most of them have never explored what's happening. Most of them

have just come off drugs and they're in treatment programs, and they don't really know where they're at or where they've come from, and it is usually anger, anger is the thing you have to deal with. Anger and fear, and fear is usually unexpressed, from my experience. They can't say, "I'm afraid," but you can see it in their faces. They know what's going on. They know they have a terminal disease. They may not tell you as fast as other groups, but they know, they know.

Fear may be unexpressed but anger is commonly encountered. Two nurses said that the reason they had left direct, hands-on nursing of HIV infected patients was because they had had to face so much anger. Because the nurse sees the patient most often, or just happens to be there, she or he gets the brunt of the patient's distress. As one of these nurses, who moved on to an administrative position, said of one of her homecare patients:

One woman was real sad. She had been an IV drug user back in the early 1980s, and she had cleaned up her act, and she was diagnosed with HIV in 1987, five years later. I've never seen such rage in all my life. This woman was so angry, and everybody could understand the anger, but we had to take turns seeing her because being in that situation, you would go in to see her, and she would just start yelling at you. The first thing she did was to start shooting questions at you to find out how much you knew about HIV. You were tested. And then she would go into these tirades. She had been mistreated in hospitals. They misdiagnosed one of her infections. She had side effects from the medication that could have been

avoided. She was one of these medical disasters. It really belongs on '60 Minutes'. It all went wrong and it went wrong in the wrong person. So she was just impossible. To deal with the situation, the supervisor would have us take turns because nobody could deal with her rage.

Patients are frequently angry and dealing with this anger is one of the nurse's challenging tasks. In addition, the nurse may find that the patient angers her. Some patients are cooperative and compliant. Some are a pleasure to care for. Some are not. They can make providing care very difficult for their caregivers. As the nurse quoted above went on to say:

No matter what you do it's wrong, and it's kind of like, "Why am I wasting my time with this person?" I hear constantly from nurses how frustrating it is because sometimes you just want to shake somebody. On the other hand, you have patients who are taking your advice and eating properly and taking their pills and everything, and then you've got this other person who's not listening to a word you're saying. He's constantly complaining about his symptoms. When you tell him to take his pills, he won't. You feel kind of nasty, and like saying, "Well, don't tell me about your symptoms, if you're not going to do a thing I say." It's like, "Why are you wasting my time?"

Patients who do not comply are a source of great tension to nurses. Patients who reject some or all of what nurses offer break the relation of mutuality which underlies nursing. Because HIV disease is bringing large numbers of patients into the medical system

who have difficulty following rules and directions, many nurses, unfamiliar with the populations most afflicted with HIV disease, are being challenged to revise their expectations of the nursing experience.

Patients are frequently from groups many of these nurses have had little contact with. They are often the poor and the despised. They are afflicted with a disease which cannot be cured, and they come from groups which are outside that which is culturally valued in America. HIV infected patients who are gay, IVDUs, blacks and minorities, or female, do not in any way conform to what Erving Goffman has described as the ideal person in American society: "a young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight and height and a recent record in sports" (quoted in Perin 1988:145).

HIV infected patients are imperfect people according to the norms of American society, and encountering them, or in the case of nurses, having to care for them in large numbers, can result in a kind of culture shock. These patients can be threatening. And they are threatening on an elementary physical level. They are contagious. Although HIV disease is rather hard to contract, it does not seem to be transmitted through respiration, for example, it can and has been transmitted through needle punctures, a common occupational hazard for nurses. The first nurse to contract HIV disease through work died in 1992.

The nurses I interviewed did not seem overly concerned with acquiring HIV disease from patient contact. Only four nurses I

interviewed and eight in the survey said they were apprehensive about catching HIV disease. Most had come to terms in different ways with the risk their patients posed. Nina H., who was working in an emergency room at the beginning of the epidemic, said:

There are still people who will tell you, "Well, you never know." I had a physician at a meeting say recently, "Well, you don't know what they are not telling us about this virus," and to hear something like that amazes me. You talk about being scared. I should be very nervous because with those first few patients, we took no precautions. We were touching body fluids constantly, blood got all over our hands.

All the nurses I interviewed said they were very careful. As one noted: "We follow universal precautions. I just got tested. I get tested every year." They do not discount the danger, but they do believe that HIV disease is primarily transmitted through sexual contact or contamination with infected blood. As Carey M. said:

I guess I've worked it out. I've been a nurse for almost twenty years, and I wonder about all the needle sticks I had that I didn't worry about before. I couldn't work here if I didn't really believe that the way the disease is transmitted is the way they're telling us.

These nurses rely on time-tested methods of infection control: cleanliness and limited contact. Some develop a feeling of fatality. One nurse said:

I think my friends think I should be more worried. I was bitten by an AIDS patient back in 1987, and I've had a few needle sticks. But for some reason I guess I'm not that

worried. If it's meant to be, I believe that if I'm meant to get it, so be it.

Other nurses find that dealing with the possibility of infection is an issue that doesn't die. It is not settled once and for all. It recurs and has to be worked through each time and a new judgment made. As Chris T. explained:

Before I took this job, I think I was actually lucky, because before I took the job I thought about all of these issues, and I sort of accepted the risks as a part of the job and I worked it out ahead of time. My family had some reaction to it, not tremendous really. My uncle asked me if I made sure to wash my hands a lot. I didn't have a lot of real negative stuff that a lot of people do have. But I was stuck with a needle. I stuck myself actually. It wasn't an avoidable accident. What I did when I took this job, I said to myself, "OK, it's spread like hepatitis, I believe the epidemiology." A lot of people didn't buy it at the time and they still don't buy it. But I did, and ergo, if I follow the precautions the blood and body fluid precautions for hepatitis, then I will be safe. But then I stuck myself through a pair of gloves, and my bubble burst. They didn't even have a test for HIV then, it was 1984. I was upset for a while, and then the test came out, and I took it and I tested negative. I was really rational and empirical about it. Nobody had come down with AIDS from caring for patients yet. I kind of looked at that and tried not to think about it too terribly much because I had chosen this work. And you know, hepatitis is a risk and it's a much greater risk

than HIV. The fact that there is a risk is not new. Nurses went in and took care of polio patients, dengue fever, cholera, etc. It seems very overwhelming now because I think we've had a long period when we felt comfortable. People expected different things from their work and one of the things people expected was that they would be safe. You think all these things through and it's a real process. It's not a process that ever goes away. I think what happens is that you get upset, you deal with it, you think about it, you learn some more and get some more information, you talk to people, you work it through and you feel better. And if something else happens, you may get some of a reaction but it's not as severe as the first time. It's sort of cyclical but it's on an upward spiral.

Many of the nurses in this study kept "working it through" because HIV disease is not an easy disease to get used to. Fear of contagion is real. Keeping the fear under control takes a number of forms. Concentrating on the comparative risks of contracting HIV disease and hepatitis is one way. Focusing on the efficacy of using gloves is another. Just trying not to think about it is another. Each nurse seems to construct her own method of acknowledging the danger but putting it into perspective. If this wasn't possible, these nurses could not do their jobs.

For nurses who remembered when infectious disease was a fact of life, the adjustment was relatively easy. Several nurses I interviewed trained in the 1950s and early 1960s and they recalled an era before antibiotics. As Carey M. said:

I'm old enough to remember polio, and I'm old enough to

remember all this other stuff that happened. When I went into nursing there was still a communicable disease hospital in lower Manhattan. I remember Willard Parker hospital where the polio people were. For the younger nurses, I don't think that's the case. I think that a lot of people who went into nursing and maybe medicine too, in the 60s, didn't bargain for this.

Before childhood diseases were conquered, people's expectations and life experiences were quite different from today, when most people expect to be healthy most of their lives. As one commentator has said:

How ordinary it was for someone to miss a year of school while recovering from a debilitating disease, to postpone a marriage while nursing a relative, to spend some time in a sanatorium. Ear infections, common in childhood, could deafen people for life. Strep throat led to rheumatic fever whose victims died young. (Smith 1990:389)

The advent of antibiotics and their widespread use in the past thirty years created the healthiest generation in history. The younger nurses in this study grew up experiencing health as a constant and illness as an aberration. HIV disease has demonstrated how unusual that was. It has underscored the vulnerability of the human body and the number of pathogens anxious to colonize it. This is a lesson in humility. As Roberta M. said:

I think most of them in obstetrics have learned to protect themselves and I think some of the surgeons have gotten out of medicine. Yet it's a very real honest-to-God fear,

when you think especially of places like emergency rooms where people are standing in blood. Five, six, ten years ago we didn't pay attention to blood, washing it off our hands, that was all. Now I use gloves all the time. I'm absolutely changed. I'm not so cavalier. I've just become a lot more respectful of the virus.

Many of the nurses I interviewed said that they actually felt safer taking care of HIV infected patients who were identified as such because they were always protective of themselves. As Lore H. said:

It's the people you don't know the HIV results of that you should be more worried about. You should take the same precautions but you may not.

Nina H. agreed. She described delaying telling her mother she was working with HIV infected patients:

I didn't tell her for quite a few months that I was working with HIV patients because I knew what I'd get and it wasn't going to be support. When I finally told her, I got exactly what I thought I was going to get, full of fear. But what I said to her was, "I know who I'm working with." When you're on the floor, and I've experienced this myself, you're just too busy, you say to yourself, "this person has breast cancer," and in your head you think, "she's not HIV," so you don't slip on the gloves when you taking blood, and yet you don't know, you just don't know. So here I think there's safety in knowing the patients are HIV infected. There's safety in knowing who you are dealing with and you take

precautions.

Precautions include being careful about mixing and administering drugs, many of which are toxic. Thirty percent (30%) of those interviewed and 44% of those surveyed said that the toxicity of the drugs for HIV disease was a concern. Both nurse and patient can be at risk when the drug is administered. When giving aerosol pentamidine treatments, for example, the chances that the nurse will inhale some of the drug are high, unless an enclosed, airtight booth, costing around \$35,000, is used. Most clinics do not have such booths.

A much more immediate concern for the nurses in the study is the possibility of contracting TB from their patients. One nurse told me that several of the nurses on her unit had acquired TB in the past year, not just turning seropositive as many nurses do, but actually developing active disease. One nurse in this study developed active TB, although she had no symptoms. Only a routine skin test, followed by an X-ray, revealed a lesion on her lung. Another nurse mentioned that pneumonia had been common among her staff during the past year. The resurgence of these diseases, particularly in drug resistant form, is very disturbing. As Lena F. said:

I don't know what's coming down the pike. I think many of these opportunistic infections, because we're hitting them with the most potent chemicals we can possibly hit them with, the history of antibiotic therapy over the years if you look at it, what happens is the germ eventually becomes immune to whatever you're hitting it with. You have to go the next step up. And with these [infections], we're using

our big guns now. What do we use when the big guns fail?

I don't know.

HIV disease challenges nurses' and patients' expectations about the course of illness and the expectation of cure. It also challenges expectations of personal integrity and autonomy because so many HIV infected patients now exhibit signs of dementia. HIV infected patients can be kept alive quite a long time, but the benefits of longevity are sometimes balanced by the negatives of brain infection and lesions which produce dementia. In their second interviews, many nurses said that the major change they had noticed in the intervening time was that now most of their patients eventually became demented. This is hard for nurses, for patients, and for families. As Bob G. said: "You don't expect people your own age to be demented."

Dementia complicates care in many ways. Demented patients do not come for appointments nor follow drug regimens. When they are in the hospital, they present many management problems. Nurses find that they have to restrain patients by tying them to their beds because the patients do not realize how frail they are. They try to get out of bed themselves, frequently falling and risking fractures. As Toby B. said:

We had a team conference this morning on one of the patients. He came in just to get some IV medication for an infection, and then he was supposed to go home, but he had a seizure. So they were working him up for a seizure, they had him all set, and he had another seizure. Now he's totally organic. He has lesions all over his brain. From being a very quiet, demure

person, he has completely revised his personality. He's very demanding, pulling out things, he's pulling out his IVs, he's frightened. When he does come into reality, all he says is, "I'm scared." We can't spend the whole day holding his hand, so we've tried to get his family and friends to come in during the day, and then at night we sedate him enough so at least he'll get some rest.

When expectations are not borne out, people often become anxious and apprehensive. Violent emotions and reactions can erupt (Mauss 1979). Disappointments produce fear as well, and from fear comes avoidance. When disappointment is extreme, people can react with repugnance and hostility in an attempt to preserve their normal equilibrium. Certainty is preferred to uncertainty.

HIV disease is a threat to the old order because it strikes at the heart of the biomedical worldview dominant in medicine for the past generation. Although the manifestations of HIV disease are getting better known, it still remains an elusive quarry. The magic bullets so effective in the last twenty five years are only partially effective against this disease and only work against its symptoms.

HIV disease does not act like other diseases and the theories on which American medicine is founded do not satisfactorily explain it. The germ theory of disease supports the notion that the HIV virus causes the disease, but so far the research predicated on this theory has born little fruit. What this does is remove one of the supports nurses have relied on in the past thirty years. HIV disease removes certainty. It replaces certainty with uncertainty.

Thus HIV disease makes unusual demands on nurses' and other

health care workers' intellectual powers. That which they thought was settled proves to be unsettled. That which they thought was true may not be true after all. What is known is only partial, not anywhere near complete. The whole of it eludes us. This produces unease, and in Freud's words, 'unpleasure':

The source of this unpleasure is the demand made upon the mind by anything that is new, the psychical expenditure that it requires, the uncertainty, mounting up to anxious expectancy that it brings with it. (quoted in Perin 1988:172)

HIV infected patients also threaten nurses' moral equilibrium, because they call into question the meanings by which we in America live. They pose a challenge to the categories we live by, categories which determine who is worthy and who is not. More often than not in New York City, HIV infected patients are the 'failures' of society. They are the poor and homeless and the deviant, in their sexual and drug behavior. HIV infected patients are not 'worthy', by American standards, and yet they require care. In caring for them, many nurses fear they may be included in the category of those without value also. (Gee 1989)

Like peoples in other cultures, "Americans attribute dangerous social powers to whatever and whomever are seen as being marginal to or in transition between clearly defined social statuses" (Perin 1988:10). Thus are HIV infected patients frequently seen as polluting and less than human. Because AIDS patients upset the usual order, they are subject to rejection, a rejection which seeks to maintain old practices and beliefs.

The nurses in this study have chosen another way to cope with

the dissonance HIV infected patients produce. Instead of turning away from these patients, they have turned towards them. They have found a way to go beyond the stigmas of race, homosexuality and drug use. They have claimed the concept of 'patient' which includes, rather than excludes, these groups. They do this by focusing on what joins them to others, their humanity, and by ignoring that which separates them, their social status.

Differences at any time have to be negotiated. The greater the differences the greater must be the effort if the differences are to be transcended or subsumed. Fears of differences are not irrational and tolerance of differences varies.

The nurses in this study have overcome the fears and distrust which a new and uncontrollable disease naturally inspires. This has been achieved through a conscious and determined effort to see HIV infected patients as first and foremost people in need, and only secondarily as gays, IVDUs, the poor and minorities. They have done this by developing a capacity similar to Keats' "negative capability - the capability of so negating their identity as to be imaginatively open to the complex and never very certain reality around them" (Crapanzano1985:xxii). In so doing, they are able to see their patients as human beings like themselves. Thus they do not fear them and do not seek to exclude them from the circle of those who deserve care.

Comparison of Interview and Survey Responses

Table 2

Question #2: What are the challenges of what you do?

Response:	N	%
1. patients' emotional needs		
interview	41	82%
survey	48	85%
2. comforting patients and families		
interview	26	52%
survey	39	60%
3. coping with patient deterioration: physical		
interview	27	54%
survey	32	57%
4. coping with patient deterioration: mental		
interview	28	56%
survey	33	58%
5. coping with patients' clinical instability		
interview	27	54%
survey	32	57%
6. working with colleagues who do not share your philosophy of care		
interview	34	68%
survey	32	57%
7. coping with death		
interview	23	46%
survey	32	57%
8. sustaining patients' hope		
interview	25	50%
survey	31	55%
9. overcoming bureaucratic obstacles		
interview	27	54%
survey	31	55%
10. social stigma of disease		
interview	23	46%
survey	26	46%
11. maintaining your own emotional balance		
interview	32	64%
survey	24	42%

12. working within limitations of care	interview	2 7	54 %
	survey	2 0	35 %
13. persevering through difficulties and failure	interview	2 2	44 %
	survey	1 6	28 %
14. coping with contagion	interview	4	8 %
	survey	8	14 %

X Providing Care

The essence of the kind of nursing the nurses in this study practice is 'to be there for their patients'. Being there for people means being open and accessible, ready to listen, to recommend, to make referrals, to see that things get done, to do things oneself. It is a stance towards patients which the nurses I interviewed described when they talked about taking a holistic view of the patient. It means considering all aspects of the patient's situation, including medical issues, family status, psychological functioning, ethnicity, sexual preference etc. It can also mean getting the mop oneself to clean up a spill rather than waiting for the aide to do it.

HIV infected patients in New York City are particularly in need of comprehensive care because so many of them lack family supports. Gay men and IVDUs are frequently single residents, and, as they become more debilitated, they become dependent on formal services for ordinary domestic requirements as well as medical and nursing care. HIV infected women are often the single caretakers of families, and they and those dependent on them need help with cooking, shopping, and paying bills, all those tasks which healthy people perform for themselves, or which could be done for them by other family members. The isolation of many HIV infected patients means that they need many and diverse services in order to live with their disease. Thus the desire of the nurses in this study to consider the whole person in their nursing practice meshes with the needs of the HIV infected patient.

This readiness to commit oneself and one's resources on behalf of another is the first step in forging a connection with patients, and a

personal connection with the patient is necessary if the nurse is to see the patient as a three-dimensional person. For 72% of the nurses interviewed and 73% of those surveyed, establishing a personal connection with patients was extremely important. Through this personal commitment these nurses approach their patients as people like themselves, a critical beginning if they are to transcend the social divisions which typically place gays, IVDUs, blacks and other minorities beyond the pale in American society. Once established, the personal connection between nurse and patient is the mechanism through which differences of class, race and gender can be negotiated.

It is through knowing the patient as an individual that these nurses individualize care, tailor it to the particular patient, and take into account the intangibles which affect illness and recovery. When these nurses reflected on their role, particularly on how their role differs from doctors, it is this aspect they emphasize. As Sally G., who was the primary caregiver in an HIV unit, said:

A lot of people, when I describe what a nurse practitioner is, everybody always says, "Oh, that's just like a doctor." I guess the thing I would like people to see is that what I do as a nurse practitioner, a lot of the things I do, do cross over into medicine; it's a really autonomous role, and you do take care of things that doctors usually do, but there are parts of that that I really believe I do better, because I think I'm much more ready to really listen to how events or diagnoses or treatments are affecting the patient. I also think I really spend a lot of time making somebody understand the

medicines or how to treat their pain or what a diagnosis means. I feel that when I'm with a patient, my patient feels like I cared about their status, and that I understand what they're supposed to do about it. I feel that my chances that this is all going to happen are better than a lot of physicians', because I think even a lot of physicians who try to do things like this can't do it as well, because they are just so far removed they don't understand why a patient doesn't understand, or what it is about what they say that patients just don't understand or can't comply with. ...What I do is assess how people are affected by their illness or affected by their diagnosis or affected by things in their lives that are making them have physical complaints. I think that I assess these better than a physician. I think it's always been nursing's strong emphasis, that's why I'm tuned into it, to be more holistic, to understand social aspects of illness or non-illness.

HIV disease has been called nursing's disease because most of the patient's needs are those requiring nursing knowledge, e.g., comfort care, pain control, nutrition and elimination. In addition, the care needed by HIV infected patients has to take into account all sorts of things which would not be strictly considered clinical, from wills to custody to homelessness. Overcoming bureaucratic obstacles to care was cited by 54% of the nurses interviewed and 55% of those surveyed as one of the major challenges of AIDS care. One nurse in a municipal hospital whose patients were mostly street people said she tried to teach her patients how to keep clean and decently fed. She saw herself as a one person referral bureau to services for the

homeless in New York City.

These nurses try to see the whole picture: they are interested in how the various aspects of their patients' lives come together and affect their illness and their care. This focus on connection is central to how they view their role. It is also how anthropologists work, looking for the way in which different aspects of a culture depend on each other. Just as the anthropologist considers social life as the expression of the interaction of a number of different systems, so do these nurses believe that a patient's experience of illness depends on the interaction of a host of factors which might appear on the surface to have nothing to do with disease. This is why Emma J. thought that nurses are in a position to make a significant contribution to how patient care for PWAs [persons with AIDS] is organized:

Nurses have always considered themselves holistic health providers who are interested in how a disease affects the person's entire life, not just whether they need lab work done, or if they need to change medicines or whatever, and there's so much room for that in AIDS, to help people deal with multiple issues like control or body image or plans or lovers or family etc. I think some of the things that are important in AIDS are things that nurses really do well.

It is not always the big things that make life miserable. It can be the conditions which in another patient would be considered minor but in an HIV infected patient become major. Diarrhea is one such condition. HIV disease diarrhea can be extremely hard to control. As Gladys R. said:

When we first started out [in the AIDS unit], we had a lot

of PCP, then we had KS, then we had TB, then everybody had toxoplasmosis, and then cryptomeningitis. We had a lot of crypto[sporidium]. If you don't really love what you're doing, you don't come back, because the smell of the stool with crypto, they had constant diarrhea, and that smell, you can smell it far away from their door. I remember one guy, I cleaned him three times in the one attempt. I cleaned him and fixed him up, then more diarrhea. I took him out of bed and I had to put him right back. You know that's so devastating to them. It is so devastating for them, and for you too, because the thing is that you have nothing to offer them. That's really sometimes the hardest part of the job. You haven't anything to offer, in the sense of being medically able to help them very much.

It is at this point that nurses begin to rely on a different set of skills. When clinical treatments have achieved all they can, what is left is human compassion. As Emily D. explained:

If you've got somebody with chronic diarrhea and they have tried every medicine under the sun, and you cannot do anything about it, and the patient's having cramping pain, it's very hard for a nurse to say this, but sometimes I say, "I wish we could do something but we can't, and maybe if you avoid certain foods, it will make your life a little easier, but it's never going to make your life pleasant again." I've had nurses say to me, "I feel like I'm not doing anything. I feel so useless, so helpless," but I found with my patients, if I said that to them, sometimes I would get anger, but

sometimes I wouldn't. Sometimes I would get a certain resignation.

Emily went on to say:

When you let people know that you really can't control this aspect, that everything has been tried, then sometimes, it's like, as long as they can complain to you about it, it makes them feel better. I had this one patient. He was always nauseous. We had tried everything, we couldn't do anything about his nausea. He would say to me, "I just need to complain about being nauseous today, just let me complain a little bit. I know you can't do anything." So I would sit there and go "Hum um" and that's all he wanted. Because the other issue too is, particularly for the patients who are well connected to other people, they realize their friends have a limited tolerance for listening to all the gory details. So one of my patients said to me, "You know if I can complain to you about how I feel, then when my friends come over, I can be sociable with them." And I would tell him, "that's one of the reasons I'm here."

There is a double vision at the center of this kind of nursing. These nurses balance two views of the patient at once. They are intent on doing all the monitoring, doing all the procedures, bringing the medication, and documenting the patient's condition. At the same time, they are alert to social and psychological factors which will bear on the outcome of treatment.

The perspective from which these nurses view their patients and from which they draw their inspiration encourages them to look

at the needs of their patients as the basis for planning instead of relying on institutional rules and regulations. Such an inclusive view of the patient as a whole person leads nurses like the ones in this study to consider and deal with issues of patient care which other health professionals, because of their narrower focus, can ignore. The nurses in this study do not feel comfortable with a narrow definition of their role. Even physicians who are caring and conscientious will draw lines where these nurses won't. As Gretchen S., who practices in a municipal hospital, said:

There are some doctors who go out of their way to help; there's one doctor here who's really gone out of his way to fill out the compassionate care forms [for experimental drugs]. There's a lot of paperwork in order to get these drugs. They're only given on an individualized basis so you have to see if the patient will fit into the category, and this doc has really tried to do that. He's very meticulous, and he's gone out of his way to get different lab values to make sure that it's all complete for someone when they come to clinic. But when I mentioned that there was a lawyer who was available, who was willing to come to clinic twice a month to deal with custody cases, he didn't want to know from custody cases. He didn't want to know, it wasn't his role. And I feel very strongly about the custody cases especially. If someone has kids, what happens to the kids after they die is very important. When you address this issue with people, you don't say when you die, you can say if something happens to you. But otherwise these kids can get knocked around in the foster care system. It's pretty awful,

and to be sure that people know that's a potential problem, there are ways to address it. I think it's very important. There are all these fathers who suddenly resurrect out of nowhere. Or one's mother says she will take them, but they never sign papers and maybe the kids go into foster care for two or three months until it gets settled. That's not a good thing. But this doc didn't want to address it. He didn't want to talk about it.

This nurse and many of the others I interviewed made it part of their practice to raise these issues with patients. Gretchen went on to say:

I try to do the topics they seem to want more, like child custody and wills. Just because people are poor doesn't mean they don't have something they want to pass on to someone else.

These nurses' concern with what the patient wants and needs leads many of them to go beyond a technical conception of their role. They are willing to help their patients in whatever way they can. And patients turn to their nurses for all sorts of help. Nora J., who spent several years taking care of HIV infected prisoners, said:

A lot of times they'll call you, not that you can always do something. One patient we had called us up when his car was taken by the police.. He failed to mention that he had stolen the car. He kept saying, "Can't you get my car back?"

They are funny. I had one patient who had a very low platelet count and other things, he was all tied up with IV lines, and he wanted to go across the street to get some money from a cash machine. This was across ---- Avenue on a Friday afternoon!

A holistic concept of nursing is most apparent when nurses look at the psychosocial aspects of illness, but it is a necessary part of the physical as well as the social care of HIV infected patients, because the disease involves so many different bodily systems. In order to provide proper care, a nurse has to be attentive to how the disease might affect parts of the body beyond the immediate site of infection. She has to keep in mind the totality of the patient's body. As Stephanie C., who had more than seven years experience in HIV care, remarked:

The disease changes. We're constantly finding new aspects of the HIV infection. I'll just give you one example. The candida esophagitis, [a yeast infection] that goes down the esophagus, we're discovering that sometimes it's not what we thought it was. There are new studies which show that it could be direct HIV infection of the esophagus as well as herpes and CMV [Cytomegalovirus]. It could be one or a combination of the above. We saw PCP [Pneumocystis carinii pneumonia] in bone marrow the other day, in a woman who recently died. It is going places we had never seen. Nobody had seen a case of it in the bone marrow before. We already look for MAI [Mycobacterium avium intracellulare] in the bone marrow and now we'll have to look for PCP.

The comprehensive concept of nursing which these nurses practice is expressed first in attentiveness to the patient's physical condition. HIV infected patients can be very unstable. Their condition can change rapidly. This clinical instability was cited by 54% of the nurses interviewed and 57% of nurses surveyed as one of

the major challenges of caring for HIV infected patients. One nurse in homecare, who said he was never sure what condition his patients would be in when he went to see them, called HIV disease "a real roller coaster". He described one case:

During the summer, there was a gentleman I would go and see every morning. I had this routine of going first thing in the morning because he lived close to me, and it made life easier. It was finished early in the day for him and for me and we were both happy. It was a Friday morning, it was raining out, and I went to his apartment and knocked on the door, and there was no answer. And of course if there is no answer, you panic. So finally someone answered and it was the man's lover-roommate. He had been asleep, and he told me that my patient had bled to death the night before. I almost freaked out. You're with death all the time, and when it takes a long time, it's not a shock, but when it's that fast, it makes no sense to you. It can be really tough when you're out there on your own.

Another nurse in hospital nursing agreed:

Certainly their disease is very unique. You learn something new about it every day, and you can see things that you don't see in anything else. You see patients who develop confusion very quickly. You'll see them fully alert and oriented at 9 am, and at noon they're gone. Patients can go from being very stable to being very critical, like in three hours. You see patients who have CMV retinitis [Cytomegalovirus infection] who see very well when they come in here, and they're blind

when they leave.

She went on to say:

You see people who come in here with what would normally be considered a simple case of pneumonia; it may not be PCP, it may be another kind of pneumonia, and they end up on ventilators.

HIV disease's unpredictability, coupled with its complexity, means that more than the usual attentiveness is required. As Ethel R. commented:

Depending on what else they're getting and the tolerance of the patient, the doctor orders this medication, and you give it to the patient. Then you walk in later and you see the man beet red. It's an allergic reaction. It's up to you, the nurse, you have to stop the medication, you have to page the doctor to come in and order the medication to counter the allergy and the reaction, and you have to go all over again with something else. Sometimes the patient will say, "I don't want it, it's going to make me sick like the other one." So you have to teach them. "No, this is a different one. You do have this infection. We have to try different medications. Yes, you are sensitive to that medicine but that doesn't mean you're sensitive to this."

One nurse compared HIV nursing to general nursing thus:

You're using your basic medical surgical skills and background; you use med-surg in everything, but then there are various signs of OIs [opportunistic infections] which you need to pick up on. With a lot of the medication, you have to watch

their renal values, you have to watch their glucose values, their pancreatic values. The medications carry more side effects too. You have to be alert to the hydration and to a patient's nutritional status, and how far into the illness they are because there are various factors that stop working in the nutritional area as they get further into HIV. They can't eat and they develop a wasting syndrome.

Patients will often have several conditions all at the same time, each a major problem. They might have pneumonia and TB and syphilis along with non-life threatening infections such as thrush or psoriasis.

In order to care for HIV patients, nurses need topnotch skills and a continuing interest in learning. They have to be alert and knowledgeable. Sixty percent (60%) of the nurses interviewed and 57% of those surveyed said that one of their satisfactions came from meeting the demands of clinical care. An administrator at one hospital told me that she had had several nurses who wanted to work in HIV, but who just weren't good enough to do it. It is complicated, complex work. Lore H., who was attracted by the complexity of the disease, said:

There are so many different systems that can be affected in any individual, and so you might have to couple respiratory therapy with cancer and with this and with that. It's so many multiple systems that can be affected. You're dealing with them all. You have to balance them all. You're thinking about what works best for the patient all the time.

As part of this effort to work out what's best for the patient, these nurses frequently look ahead to what the next level of care

should be. They anticipate and initiate. Gretchen S. noticed at her hospital that more women were appearing with HIV disease, and so she instituted regular pelvic exams for her clinic patients over the objections of many on the HIV clinic staff; they wanted to send them over to the regular OB-Gyn clinic. But Gretchen said:

The physician assistants thought I was crazy when I tried to do the pelvics. I got a real sense that people really thought I was crazy. People said, "Why would you want to do that for? Why bother, it's yucky, are you crazy, just send them downstairs."

But according to her code, this nurse would have been remiss if she hadn't done pelvic exams, since infection in women often manifests itself in the reproductive organs. Another nurse said that the infectious disease doctor in her hospital didn't even order a gynecological exam for a female patient who came in with a fever until the nurse suggested it. This is certainly doing for the patient what she cannot do for herself, but what she would do if she had the nurse's knowledge.

Along with attention to the patient's physical condition, these nurses strive to keep the patient in touch with life and with normality. Fifty percent (50%) of them and 55% of those surveyed saw sustaining the patient's hope as part of their job. This can be as simple as a bath and a short trip outside the room. This is how Gladys R. described what she enjoyed about nursing:

I love bedside nursing. Yes, I do. I like to be able to see my patient get well and go home, or my patient is sick and needs my help. I'm there to give the help he needs, to help that

patient get over that hump, and I'll look at him and he might say, "Thank you, I'm feeling much better today. Yes, my breathing is better." And I say, "OK," and I brush their hair, or comb their hair, and clean them up nicely, and sit them up, and say, "OK, I'm going to take you out of bed for half an hour." I take them down to the patient's lounge in a wheelchair, and let them sit there, even for five minutes, and then bring them back. It gives me great satisfaction to know I did this, and that it helps the patient. At least they had a little bit of life again.

By doing this sort of thing, these nurses keep their patients within the circle of social value. They strive to maintain their patients' social place and meaning. They do not limit their interaction to a formal exchange of information. Lena F. described clinic days as "fun"; Gretchen S. said:

I don't have that much time with them. It's not like I have a whole hour to talk to people, but people know that I am there in some way. Clinic is really crazy. Sometimes I'm really ditzy, because I'm always forgetting something, and I tell the patients to remind me. "If you want a chest X-ray, remind me," "if you need Motrin, remind me again." It's really a chaotic scene. It's not really a scene which is conducive to any kind of real thoughtful processes, because while I'm doing all this, I'm trying to maintain the energy for people, because I have a lot of energy myself. I try to let people know that they're special. When I come through the waiting room, there are some that I know, and they greet me, and I greet them.

I don't stop and chat, I don't have time, but I'll say, "You look great today!" or "It's a great shirt you're wearing." That's not unnoticed, that I don't just walk in and pick up the chart. And I've gotten stuff back because of that, someone last week said, "Thank you, just thanks for being there for all of us." And he wasn't even my patient.

Stephanie C. arranged for a patient to display his photographs in the hospital. She wanted him to feel that he was still a productive and contributing member of society. She said:

I have a patient who is a very talented photographer, very artistic, and very bored. He's going to be in the hospital for three weeks; he has toxo [Toxoplasmosis] and he is going to get medication. And we're going to work him for other things too, like possible CMV retinitis. But he has photographs of Liz Taylor and Tina Turner. He's had exclusive sessions with them. He's really very talented, and so right now, we're planning a show for him in the hospital. It's important to him. The message he gives me is that he wants to keep active, professionally and personally.

The concept of nursing which the nurses in this study embrace makes it easy for them to see their role as helping their patients move comfortably from one state to another, whether that transition is from sickness to health or sickness to death. These nurses encourage their patients to maintain a normal life as long as they can, but with HIV disease, there comes a time when preparing for death becomes necessary.

A good death is the last gift the nurse can give the patient.

Coping with death was mentioned by 46% of the nurses interviewed and 57% of those surveyed as a major challenge. Paula T. described herself as becoming "the death nurse in her hospital," and Agnes S. remarked, rather ruefully, that she seemed to have a talent for death. Keeping patients company while they die is a last act of connection and the ultimate recognition that they are valued. It can be the most intimate experience of all, and it can be as important for the nurse as for the patient. Carol H., who had little experience of death before she became an HIV nurse, said of the first HIV infected patient she cared for who died:

I remember the first one who died who I was very close to. I think what made him special was that he was so at peace with himself. When he died, it was OK, and death then was very new to me. I was rather unusual in that most people who come into AIDS work usually have some experience [with death], but I didn't. I knew no one who had AIDS, so it was all new. And you're really sharing, it's really intimate. They let us in. They let us in so readily, and that's really extraordinary. As I sat with him as he was dying, it reminded me of sitting with women in labor, giving birth. It's a very intimate experience. You don't know when it's going to happen, and you have to have the patience to wait for it. And it's momentous. It's happening and you have to give yourself to it.

Several nurses said that some patients wait for permission to die or wait for their favorite nurse to be on duty before they die. Toby B., who nurses in a voluntary hospital, said that the staff and

most of the patients on her unit were very honest about death; that enabled them to work towards "good deaths". As she said:

We got into helping people be comfortable about letting go and talking about it and letting them know that it was OK. I don't believe in mercy killing, so you can't do that, but you can certainly give someone permission to let go.

Some nurses recognized that their role continued beyond death. Many of them became the link between the patient's past, his present, and his future. Like Dr. Rieux in Camus' The Plague, they saw themselves as among those who "should bear witness in favor of those plague-stricken people; so that some memorial of the injustice and outrage done them might endure; and to state quite simply what we learn in time of pestilence: that there are more things to admire in men than to despise" (1948:178).

The nurse who arranged for her patient to show his photographs also proposed a program for patients themselves to create a record their families could retain. She tried to organize up a program in which patients could produce their own videotapes so that their families, their children particularly, could keep an image of what they were like before they became terminally ill. She said:

One young mother looked me in the face, she was holding a two year old by the hand, and she said, "He won't know who I am. I'll be dead and he won't remember me. He won't know what I look like, he won't know where I came from." And I had an epiphany, you know, like James Joyce, and I had this picture of this whole thing, that if we could capture these women doing a sort of family review or whatever it is they

want, if they could put their own narrative down on tape, that this would be a help to them.

So, of course, do many anthropologists think of themselves as historians of those without a history. Part of their role is to make sure people are not forgotten. For these nurses, every patient has a narrative, and preserving the narrative can become very important.

Operating on so many different levels at once, the physical, cultural, social, psychological, is both the source of these nurses' pleasure and the source of their greatest tension. Nurses who practice holistically have to use their minds and their emotions, but they must not let their emotions run away from them. This is a tension common to anthropology as well. As one anthropologist noted: "too much empathy can lead to overwhelming feelings of vulnerability and uncertainty" (Johnson 1991:16).

In fact, feeling too much can run counter to nursing's goal and to the patient's health. Sixty four percent (64%) of the nurses interviewed and 42% of those surveyed said the maintaining their own emotional balance was difficult to do. Arthur R., who worked in an HIV unit where patients came back for treatment time and time again, explained it this way:

I was trying to explain to my assistant the other day that you cannot be emotionally involved, because then you might not make the proper decision. You might use your own defense mechanisms and say, "Well, this is happening, but it's really nothing," whereas it should be looked at. Or you might want to believe that everything's going to be fine, so you don't pick up on things, and then you're not doing the patient any good.

And also, when they tell you, like this one guy said to me, "I want to stop everything," you might not be able to deal with that if you're emotionally involved. You might say, "Oh, don't talk like that," or "you're crazy," when actually the patient needs to talk to you. So you have to maintain a certain distance, you can't totally identify like it's your family or friends.

Achieving the proper relationship, not too close, not too distant, is not easy. It is a task similar to that faced by the fieldworker who wants to get to know the people being studied, but who fears being enveloped. Getting too close can mean the loss of critical distance so necessary if proper judgments are to be made.

Both nurses and fieldworkers have to be able to observe the people they are caring for or studying without preconceptions and prejudices, but they must note ethnic, biological, religious, racial, sexual, economic, and social characteristics. They must be ready to admit similarities between themselves and those others who are different, yet they must be aware of what the differences mean, and how they affect their interaction. They try to feel close to their patients or their 'people' but they must be wary of overidentifying. For both HIV nurse and fieldworker, the experience of work is emotionally draining, because so much that is different has to be absorbed and understood. It is a 'total' experience. It is also exhilarating because it offers practitioners an escape and a release from their own conventions of thought and behavior. By learning who the 'other' is, they try on other ways of being human, and in the process, discover a wider range of human possibility for themselves.

Comparison of Interview and Survey Responses

Table 3

Question #5: What keeps you going?

Response:	N	%
1. pleasure from patient contact		
interview	26	52%
survey	45	80%
2. feeling that work is meaningful/needed		
interview	38	76%
survey	44	78%
3. personal growth		
interview	37	74%
survey	36	64%
4. "making a difference"		
interview	39	78%
survey	36	64%
5. commitment to providing healthcare for all		
interview	33	66%
survey	36	64%
6. helping others		
interview	34	68%
survey	30	53%
7. clinical interest		
interview	16	32%
survey	30	53%
8. having interests outside work		
interview	9	18%
survey	23	40%
9. feeling of identification		
interview	7	14%
survey	11	19%
10. support from family and friends		
interview	8	16%
survey	11	19%

XI Dilemmas of Care

These nurses' focus on the 'other' provides them with a cognitive framework for solving many of the ethical dilemmas they encounter in the care of HIV infected patients. Most of these dilemmas center around questions of treatment. Because HIV infection is not fully understood, treatment is, to some extent, always problematic. Because the drugs used are very toxic, there is always the possibility of serious side effects as well as the possibility of improvement. The principle on which the nurses I interviewed relied for guidance in these situations was that the patient should be the one to decide, on the basis of informed consent.

The issue most nurses mentioned when I asked whether they faced any ethical dilemmas was the question of terminating treatment. Sixty four percent (64%) of the nurses interviewed and 51% of those surveyed cited ending treatment as an ethical issue. Nurses are not, by and large, in favor of aggressive treatment at all and any cost. This is certainly true for the nurses in this study, although the nurses I interviewed fought long and hard to get their patients more time. A week at home, even if the patient eventually returned to the hospital, was a victory. But they all believed that a point comes at which treatment no longer produces a benefit. 34% of the nurses interviewed and 51% of those surveyed said that recognizing the limits of hi-tech medical care was one of the ethical challenges they faced. When the point came when treatment became counterproductive, care should begin to focus on making the patient comfortable.

This can run counter to physicians' instincts. I was told that

some physicians will continue to recommend aggressive procedures such as lumbar punctures for patients at the very end-stages of HIV disease. The nurses I interviewed, however, because their attention is so firmly on what is happening to the patient, are more ready to acknowledge the moment when treatment should logically stop and more ready to talk to patients about death than many of the physicians they work with.

Many told me that they discussed death and dying with their patients. Emily B., practicing in homecare, said it was always a question when a new infection cropped up or an old one flared again. She said:

I found that once I established my credibility with the patients, they would use me as a sounding board. They'd ask, "Should I do this treatment? Should I ignore these symptoms and let myself die?" Somebody would develop a new infection, and they always had to make the decision whether or not this would be the infection they would ignore and let kill them, so more than once I would find myself having a discussion with somebody, "Well, you've got pneumonia, OK, what are you going to do about it?" And they would ask me very bluntly, "if I die of pneumonia, what's it going to be like?" I would explain that we'd order oxygen and control the symptoms. I'd explain we wouldn't let them lie there gasping for breath. We'd make them comfortable, because everybody is afraid it's going to be a painful process.

Helping patients choose the manner of their dying is a natural extension of these nurses' philosophy that their role is to look ahead

for their patient, anticipate what is coming and make provision for it. Thus these nurses will bring up the question of DNRs (Do Not Resuscitate orders) but do it in such a way that respects the patient's right to choose. Some will choose one thing, and some another. Fifty eight percent (58%) of the nurses interviewed and 53% of those surveyed said that DNRs represented an ethical dilemma. Stephanie C., who was particularly sensitive to the delicacy of the undertaking, explained how she approached the issue:

Of course, some of them want to have every effort made to maintain life, and that's OK too. As a health professional I can put that hat on, and I can say, "Well, the better thing for you would be a DNR (Do Not Resuscitate) order," but the other part of me, as a nurse, says that the coping mechanisms of the patient have to be respected. ... Some patients have denial to the last minute, to the last breath. Some patients tell you in an unwritten message, in a sort of metacommunication, that the way they want to die is to fight to the last minute, and not give up, and do everything possible to maintain life, and they want to be intubated [on an artificial ventilator]. That's OK if they want that, that's their choice if they want to die that way, just as long as they have the information there, so that they choose how they want to die. ... Right now, it's important to me that the patient has as much information as they need to make their choice. We tell them what it's like. The doctors are sometimes uncomfortable telling patients. Many of the jobs which are relegated to nurses are mop-up tasks, and one of the mop-up duties is to tell the patient

what's really going to happen, what having KS [Kaposi's sarcoma] of the lung means, which is that the tumor is going to grow and grow in spite of the chemotherapy, and eventually what will happen is that there will come a time when we will have to make a decision with you to intubate you, and put you on a machine, and do everything possible to save you. I give them the odds that they will never come off the machine. I say, "You'll spend two weeks of your life hooked to this as you die, or we can keep you comfortable and give you oxygen and comfort measures, and your family can be with you, and you can talk with them." It's really awful to be on a machine, but we try to be fair about the presentation. I think that many of them appreciate it. They say, "I never knew that, and let me think about it." Fine, we have time. I guess we're learning more and more to get to people earlier so they can make these decisions.

The new New York State health proxy law is another question many nurses now raise with their patients. The law permits patients to nominate another person, not necessarily a family relative, to make medical decisions for them if patients are unable to make a decision themselves. This is a patient-centered approach to nursing in which the locus of decisions is the patient. The nurse gives the patient as much information as she can, in a way that the patient can understand, but the final choice remains the patient's. This both flows from and supports these nurses' conception of nursing.

Many of these nurses see their role as helping their patients move comfortably from one state to another, whether that transition

is from sickness to health or sickness to death. This understanding is a gradual one. As Cassie N. said:

When I first became a nurse, so many of my friends thought I was nuts, especially when I talked about my patients. I was so enthusiastic. When people asked me what I did, I said I saved lives for a living. But with AIDS patients, I can't say that. What I say now is that I help them maintain their quality of life for as long as possible. When that's no longer possible, I help ease them into the transition into death. That's what I have to say now. Because you don't save anyone with AIDS. You prolong their lives as long as possible, you keep them as comfortable as possible, you make them as well seducated as possible about their disease, and when none of that is possible anymore, the only thing you have left is to keep them clean and comfortable on their way out. Help them make that transition. Help them decide how they want to be buried. Do they want to make a will? Do they want to contact people? Help them face these issues, if possible.

Such a conception of the nurse's role makes it easier for them to face death with acceptance, but it does not mean that having patients die is easy. As Stephanie C. said:

It's very sad. For a while when you have a newly diagnosed patient, the struggle is to keep them healthy as long as possible, and that's great, and that works sometimes. Then sometimes out of a clear blue sky, unpredictably, a patient will come down with a very serious opportunistic infection, something that we hadn't foreseen, and will get extremely

ill. The patient looks at me, and I look at them, and we both say to each other: "This is not fair. It's too soon."

Witnessing and not being able to prevent such suffering is hard to bear. As one nurse commented, "It's not death, it's the dying which is so hard to take." Once a patient is hospitalized with an opportunistic infection, nurses know that a first hospitalization will be followed by a second and a third. Bob G. described the disease as having "milestones": the diagnosis, the first medication, the first hospitalization, the wasting. Each of these milestones is a sign to the nurse of what is to come. Nurses watch their patients become shadows of their former selves, both physically and psychologically. Marilyn D. said this is very difficult:

I've seen a lot of people who progressively, over a year, they get thinner and thinner with rashes and lesions and whatever. They really lose all of their well being and they're just shells. Some were very vibrant, and that's sad, discouraging, really the hardest thing to watch. They just sort of fade away and become, at thirty or forty, walking around with a cane, like someone who is ninety.

Watching this deterioration is not easy. Fifty four percent (54%) of the nurses interviewed and 57% of those surveyed cited patients' physical deterioration was a challenge. Fifty six percent (56%) and 58% respectively felt the same about patients' mental deterioration. Nina H. said:

I don't think death is the hardest thing in the world. I think a lot of the dying in between is. Patient after patient tells me that they have accepted the idea that they are going to

die very soon. What they can't accept is losing control, or losing their independence, or losing their mind, or losing control of their bowels, or losing their friends who don't come to see them anymore. That's what I think people have a harder time with than death, and it's what I have a harder time with than death, to watch people go through that. There is a patient in the hospital right now who came in and was treated for PCP with a drug that can really cause a lot of damage to your pancreas. Well, first he got the side effects and now what it caused is that now he's an insulin dependent diabetic. So he got over his pneumonia and had to come back in the hospital for his diabetes. They got him under control and taught him how to do his insulin. He kind of appreciated the diabetes because it was a disease he could manage. He controlled his blood sugar pretty well, but now he's back in the hospital with CMV retinitis. It means he's going blind. He'd only been home about three weeks and now he's back in the hospital. He has to have a Hickman catheter [a permanent catheter for IV treatments] and daily infusions [of drugs] for the rest of his life. He has to have an IV infusion every day to prevent blindness, and it's as though he has limited his wants, his desires, to keeping his little studio apartment and not having it look like a hospital room. Now he's going to have a nurse coming all the time. He's going to have to have hospital equipment. He's going to have to have a home health care attendant because he's really feeling overwhelmed. He really can't do it all, and all he wanted was to be able to

stay home in his little place and not have it one big mess.

But it's just one thing after another.

The sense of holding one's finger in the dike while leaks spring up all around is strong. One infection is brought under control and another emerges. Quite often treatment itself can produce the next problem. As Marcia B. said of one of her patients:

I have one young man who's been doing extremely well for the past four years, and he has had six bouts of PCP and come through all of them with the same energy he went into them with. He does very well, but he has these bouts and in trying to control them they put a central line [permanent catheter] in, and every six weeks or so he gets several days of IV antibiotics to try to keep this PCP under control. He's done the aerosol bit and he still gets it back. Recently his central line got infected, and in treating him with antibiotics, he became allergic to the first one. So they tried another, and he was allergic to that one. I have to go down to medical records today and pull out a list of all the antibiotics he's had to which he's become allergic because the doctor wants him to wear a medical alert bracelet because we can't keep track any more. They've used practically everything under the sun on him. If he gets another infection I don't know what we're going to use.

Similar questions of when and how to treat cluster around HIV infected patients who are pregnant. Ten percent (10%) of the nurses interviewed and 26% of those surveyed agreed that pregnant HIV infected women present ethical questions. It used to be thought that

a majority of children born to HIV infected women would contract HIV disease in utero, but this has been shown to be false. The infection rate is 20 to 50% (Bayer 1990). It was also thought that being pregnant would accelerate the course of HIV disease, but again, this has not proved to be so. (Novick 1991) So, although the most frequent medical advice for HIV infected women is to either avoid becoming pregnant or to terminate the pregnancy, the chances of having a healthy baby are quite high. Sometimes against many odds, choosing to continue a pregnancy has a happy ending. Carey M., who co-ordinates care for women in a perinatal HIV transmission study, told the following story:

We took care of a woman who came to New York to get medical care for her two year old who had AIDS. Her husband was in Brazil dying of AIDS, and she was HIV+ but not sick yet. She was pregnant when she arrived, and in her eighth month, she had PCP [*Pneumocystis carinii* pneumonia]. While she was in the hospital with PCP, her two year old died, and she went out on pass to the funeral. It was the most incredibly heart-breaking thing. She had this kid [the one who died] who was neurologically impaired and a real gork, and the mother just cared for that child, and she was pregnant, and we all sort of went through it with her. She was really religious, and we went through her agony over whether to have an abortion or not, and she finally decided she had to keep the baby. She's one of the few people that I really believed that it was for spiritual reasons or religious. Most of the time people say it, and you find out they had two abortions previously. She

was a person we really watched go through her own spiritual struggle over this. She had the baby, and found out a week or two later that her husband had died in Brazil. It was just dramatic, talk about courage, and her little baby is two years old now, and she is not infected.

Nurses have to keep in mind that this can happen, at the same time that they recognize that this outcome is not guaranteed. Other patients may not be so lucky, but again, it is not for the nurse to tell them what to do.

A further complication with pregnant women who are HIV infected is the question of whether to put them on AZT [azidothymidine], which at the time of this study, was the only Federally approved drug for HIV disease. AZT may help the mother, but there is no definitive information yet about its effect on the fetus. Similar problems surround the prescription of Bactrim for PCP [Pneumocystis carinii pneumonia] prophylaxis. What may be good for the mother may harm the fetus. The nurses in this study who cared for mothers and newborns, in the absence of certainty, left the final decision to the mother.

This is a different perspective from that of many physicians, whose instincts are to recommend action and therapy (Payer 1988). This instinct is certainly not all to the bad, but the nurses in this study believed that it should be modified to fit the individual case. Alice D., who has over 30 years of experience in hospitals and private practice, explained why she thought some physicians resisted recognizing when the moment to cease treatment arrived:

I think physicians' mind set is that they want to cure people,

or they want to delay the dying as long as they can, and that's a noble and admirable quality. I wouldn't want it any other way. But I think sometimes they lose sight of the fact that sometimes they're almost causing more discomfort. Here's the scale of balance. How much do you give to try to delay the progress of the disease, and at the same time, you're decreasing the quality of life of that person. How do you do that and try to maintain some kind of quality of life? Here I think informed consent is important. You make decisions with the patients. Some patients will say, "Look, do what you have to do. I'll put up with the nausea and the vomiting and the diarrhea and whatever. I want to hang in there, because how knows, tomorrow there might be a cure and I want to be here for it, whereas other patients will say, "Look, this is not a life, this is no way to live."

Similar conflict arises over pain relief. According to these nurses, many of the physicians they work with are often reluctant to prescribe large amounts of pain medication. They are concerned about addiction and the possibility that opiates can depress a patient's breathing, bringing death a little sooner than it might if lower dosages were administered. Sometimes, however, there seems to be a callous disregard for patients' suffering. One nurse, trained in Europe, was upset by the agonized deaths she witnessed on her unit. She said many patients did not receive enough pain medication and so died in great pain. There is no need for anyone to die this way, but it does happen. Stephanie C. described an episode in the pediatric unit which she felt should never have happened:

A little boy I remember, a three year old boy, who was in great pain. I know that he was in great pain, he was dying of AIDS. We had his crib full of stuffed toys. He loved stuffed toys. He had so many he was actually lying on them. His mother and father abandoned him, and so he became ours. We used to get him out in the wheelchair, and he would whimper. His belly got so big, it was his liver, everything was going wrong with him, and so I got them to give him some oral morphine, by drops. They gave him the oral morphine, and I will never forget this, the neurologist came up the next day and said, "Don't drug this kid, the child's not in pain." And in the meantime, when we would pick him up under the arms to put him into the wheelchair, he would scream. ... We had known this child from the beginning, from the first time he walked through the door. So we watched him progressively get sicker and sicker, and we knew when he was in pain. We knew that it was not like him to sit there and say, "uh, uh, uh," that kind of thing. It was true that the child would nap on the morphine. He would doze, but after a while this effect wears off, after the body adjusts. At any rate, the neurologist didn't like that, he was the Chief of Neurology, so he said, 'I want you to cut out the morphine and I don't want this child drugged, this child's going to live a long time, etc. etc.'" So all the doctors said, "The chief said that, you know," and they cut out the morphine and the child died in agony after two days.

But for the nurse who told the story of the little boy who died

in agony, that was not the end of it. She used the episode to prevent similar tragedies. As she said:

I talked until I was blue in the face, and the pediatricians were all frightened of crossing the hierarchy. They didn't want to start trouble, but you see, this is not going to happen again. I will not let it happen again. I will remind them of this. I will use it as ammunition, so that this child who died in agony, it is not going to happen again. We should learn from him; he was a good teacher. He taught us a lot. Let's not do this again. So I will fight like a tiger for the next child to come in. That child will go out sedated.

These nurses see themselves as the patient's advocate. Part of their role is to present the patient's point of view, particularly in cases when the patient cannot advocate for himself. In order to be the patient's advocate, however, the nurse has to know the patient well, and this is something which HIV disease makes possible. Because HIV infected patients have frequent hospital admissions and need continual care in various settings, they are well known to their nurses.

It is this back and forth process, of being admitted to the hospital, getting treatment, going home, getting sick again, and being readmitted to the hospital which makes HIV infected patients and the disease they suffer from familiar to the nurses who care for them. These patients are not just diagnoses but individuals with lovers and families, who are trying to hang onto life as they knew it before this disease took them over. It is also the reason why many of the nurses I interviewed said they found satisfaction in caring for

HIV infected patients. Gladys R. said this was indeed part of what appealed to her:

[In other kinds of units} they go off into the sunset, unless you work in a small hospital and your clinic is right there and you see them coming to the clinic. When I was working in the dialysis unit, when dialysis first opened, we used to follow the patient from the clinic visit to the dialysis to the transplant and then to the clinic visit again. It was nice. Then it got so big that all we did was dialysis. Somebody else did the transplant, somebody else had the clinic, and I lost interest in it. You never saw your patient again. So then I said that was it.

Gladys found the sense of community in HIV care which she had enjoyed in the early days of the dialysis unit. In her AIDS unit, she said:

It was like family, it was family. We used to sit in the room with the patient. They'd be watching TV and we'd be sitting there writing in the chart. And we could observe them, because I could be writing and then I'd look up and then I'd write again, and look up, and I could see exactly what was going on, because you take care of them, you bathe them, you set them up, and after lunch is when you'd sit down and write charts. You'd sit in the room and you'd write, and then you could observe anything that was going on. If there was a change, they'd change right in front of your eyes.

Many (52%) of the nurses I interviewed and 80% of those

surveyed said that the pleasure of patient contact was something they sought and something they found with HIV infected patients. It enabled them to see their patients as people, a necessary step if they were to transcend the social characteristics of many of their patients. Familiarity is essential if the nurse is to understand the HIV infected patient. Such a relationship is neither so easy to achieve with other patients, nor so necessary. As Robin M. said:

I did critical care for many years and there is no on-going relationship with the patients. That's why I chose it, I wanted to be technical. I wanted to look at the monitor and I wanted to do this high-tech stuff, like someone comes in with a heart attack, and I jump in and do my heart massage, and defibrilate them, and I save them. It was a lot of action, and I liked it, and I still really like that action, and I miss it a bit. But on the other hand, I never had to think so much about any patient's lifestyles or where they come from. The main thing was they should not be in danger. There was a lot of counseling and telling them what to do and not to do, but they would leave and I would not know who they were anymore. But here everything stays with you.

Once established through repeated contact, the personal connection between nurse and patient is the avenue through which differences of class, race, and gender can be negotiated. As one nurse said of the minority women she cared for, "I give them my home number; they call me by my first name. I try to be their friend."

For many nurses this personal relationship is why they went

into nursing and why they stay in it. It is also the cause of a great deal of tension. The nurse wants to be connected to the patient, to be understanding, to do what the patient wants, or to do what will help the patient. But often, and particularly with the HIV infected patient, the needs of the patient, especially the emotional needs, can be a source of conflict. As Marcia B. explained:

I can think of someone who's on the unit right now who I feel is extremely needy, and a lot of it is really an intense loneliness. There are people who feel extremely lonely and I think that's the most difficult thing to manage [for a nurse]. It's almost like no matter what you do, you see that patient, and you start to feel guilty because you haven't met that need. So I think that's what makes nurses draw back. They say, "I know you want me there, but I'm doing something else," and then they feel guilty. It's easy then to think, "I don't like you [the patient] very much," or "I don't want to be around you any more." I can understand that, that some people are so overwhelmingly needy. Sometimes it helps, it depends on the patient of course, but there are some patients you can say this to: "I want to be here for you, and I recognize that you are lonely. I want to spend time with you, and I feel bad I can't make it all go away for you, but I have to go take care of other patients, and I'm afraid you're still going to be lonely when I leave." To acknowledge the way you feel helps the patient, and I think it helps the nurse as well, instead of just trying to give what you can and run away and feel kind of bad about

it. But there are definitely some patients you pull back from.

Some nurses felt badly that they pulled back from patients, and that they pulled back from patients at the end when they felt the patient needed them most. But it was important that they preserve their own sense of self even when they wanted to act otherwise. One nurse said:

You see someone coming, he's PCP, first admission. OK, it's very easy because it's nothing threatening, but you see him at the end of the disease, where you've known this guy for maybe 18 months or a year. You see him disintegrating, and there's nothing left. There's only a shell of what you knew before. And it's very hard to reach out to that person. It might just be me, it might be just a personal issue with me, but I don't think so. I think it's more than me that sometimes, when someone is so sick, it's so hard to reach out.

You may want to, but to be able to is another thing.

Another nurse had exactly the opposite problem. She found herself becoming too close to her patients and had difficulty maintaining separation. She envied nurses who could maintain boundaries. As she said:

Being in administration is safer for me, although I loved bedside nursing. The costs were too high, at least for doing it all the time. I'm one of these all or nothing people, and that tends to get in your way a lot. I would have drawn back [from patients] if I could have. I'm at the other end of the spectrum to the nurse who wasn't able to control pulling back. I wasn't able to control the investment. The

other, if I could have had my druthers, I would have preferred that. Maybe there's a cost to the patient there, but I'm not sure there isn't a cost to the patient also with the nurse who overinvests herself. That's something I recognize.

The cumulative effect of caring for HIV infected patients can be depression and despair when there is so much to be done and so much to feel. It is difficult to keep on providing care while coping with the intellectual and emotional demands of the disease, the patients, and other caregivers. What many nurses report is that after holding up for a long time, the death or deterioration of a particular patient triggers a violent reaction. As Emily D. said:

It's funny how it snowballs. I took care of [HIV infected] people for years and I was functioning just fine. Then there was a group of people I got particularly close to, for whatever reason you always identify more with some people than with others. I lost three of these patients in one week, all of them were long term people, like upwards of two years. One was expected to die, one chose to die, and he was all prepared, but one was totally unexpected. I got to the home, and the lover answered the door; he had come home for lunch and found him dead. That was horrible. In the third case, the sister was the caregiver and she was clinging to him to the point of absurdity, but he was feeding on it. This guy had KS everywhere. He was all swollen. His legs were swollen, his scrotum was swollen, he was miserable. He was on morphine round the clock and he was still miserable. Yet he couldn't let go to die. She wouldn't let

him go. It was totally unbearable. It was gruesome. He was suffering too. Then he died finally, and what happened to me was I hadn't let myself mourn any of the other losses, and it all came crashing down me, and I started to cry for everyone.

The emotional strains of nursing, particularly nursing a new and infectious disease, demand great self-control on the nurse's part. She has to be able to temper her responses, both towards and away from the patient. She has to be sympathetic, but not too sympathetic. She has to be clinical, but not solely clinical. It is a balancing act, one which 64% of the nurses I interviewed and 42% of those surveyed cited as a challenge. The nurse doesn't want to shortchange the patient, but at the same time the nurse needs to retain her independence and her autonomy.

Most nurses, when asked, will say that the personal connection with their patient is central to their practice. It is, certainly for the nurses in this study, the avenue through which they achieve their nursing goals and their professional and personal satisfactions. Through their personal connection the nurse and patient mesh their viewpoints, the one to help the other get well. Yet that personal connection contains the seeds of many conflicts. In order to resolve those conflicts with due regard to each party's interests, nurses have to have a developed sense of their own self, as well as an understanding of their patient as an individual. Being true to one requires being true to the other. One does not preclude the other. Establishing the proper boundaries is essential if the experience of care is to be beneficial to both the protagonists in the encounter, the

nurse and the patient. The nurse has to be present to the patient as an individual also. When this happens the nurse feels the same support as she provides the patient. In some fashion they take care of each other.

Comparison of Interview and Survey Responses

Table 4

Question #4: Do you meet any ethical issues in your work?

Response:	N	%
1. access to treatment/drugs		
interview	33	66%
survey	35	63%
2. DNRs (Do Not Resuscitate Orders)		
interview	29	58%
survey	30	53%
3. termination of treatment		
interview	32	64%
survey	29	51%
4. recognizing the limits of hi-tech medical care		
interview	17	34%
survey	29	51%
5. maintaining confidentiality		
interview	19	38%
survey	28	50%
6. toxic medication		
interview	15	30%
survey	25	44%
7. notifying partners/family members		
interview	13	26%
survey	20	35%
8. encountering suicide requests		
interview	9	18%
survey	19	32%
9. pregnancy decisions by HIV+ patients		
interview	5	10%
survey	15	26%

XII The Rewards of Care

Nursing which takes into account every facet of a patient's life is difficult work, so it is not surprising that many of the nurses I talked with entertain thoughts from time to time of leaving nursing. One said, "Every Friday I think about quitting." Some actually have left nursing and then come back, because there are rewards in nursing which they cannot find in other occupations. Carol H. stated forthrightly, "All of us do this because we get something out of it." As Carey M. said:

Sometimes I say I want to open up a fast food store in the country, but I think what still sustains me, is the fact that I am doing something for humanity in whatever small way it can be done. And it's not just what I know how to do but the fact that I choose to do it. That's the satisfaction, knowing that I'm doing something really important and perhaps giving a group of people something they wouldn't have otherwise.

Most (68%) of the nurses I interviewed and 78% of those surveyed described their work as "important" and "worthwhile". It is important because it deals with serious issues, with life and death, with illness and health, with hope and despair. HIV disease is also the medical crisis of our time and through their involvement in HIV care, these nurses are a part of an experience unique to the last decade of the twentieth century.

HIV care is worthwhile because the nurse can effect improvement and change. Although there is no cure, the treatments for opportunistic infections have improved greatly since the early 1980s and nurses have the satisfaction of being able to alleviate

many problems. As Stephanie C. said, "Now at least we can make certain predictions, we know what helps and what doesn't."

Thus, on the first and simplest level, the rewards of doing this kind of nursing begin with the patient's reaction. If the patient appreciates the effort the nurse is making and expresses that appreciation, the nurse knows that she is doing a good job. As Emma J., in charge of AIDS patient care in a suburban hospital, said:

Everybody smiles when I walk in the room. I get a satisfaction out of being one of the few people they are able to talk with and confide in, and someone who can give them a small amount of comfort, or small amount of help, in a world that is just beating up on them. The satisfaction I get is that really I have not found anybody who is not happy to see me. Everybody when I walk into the room says, "Oh I'm glad you're here." That's enough.

Such a reception can be a boost to a nurse's self-esteem. It can make the hours and struggles all worth while. As Bette V. said:

Personally, to me, there are great rewards in it. It's wonderful to your ego lots of times. People are so appreciative, and so sweet, especially AIDS patients on the whole. 99% of them, perhaps they've been places where they weren't taken care of well, or they've heard stories about not being taken care of well, and they appreciate the least little thing.

For these nurses, most of whom remember the disdain with which nursing was viewed until quite recently, expressions of appreciation are sweet indeed. Fifty two percent (52%) of the nurses interviewed and 80% of the nurses surveyed said that the pleasure

of patient contact sustained them. In addition, being able to do it right, and to do it for people who don't expect it, can be a pleasure in itself. For Maria J., whose patients were all IV drug users or the partners of IV drug users, it is this aspect of what she did which kept her going:

Patients tell me, "I'm glad I met you". They will say they never had anyone care for them. The patients here don't have families. They've used drugs and everyone has disowned them. Or women have been infected by people who used drugs and they still disown them. People here don't ordinarily seek medical care. They tell me I made a difference. Just when I think, "Oh, I don't know if I can continue to do this", then I hear something like that and I say I have to continue. I have to because I think I make a difference.

This phrase, "making a difference", recurs frequently when these nurses talk about the satisfactions of HIV nursing. Seventy eight percent (78%) of the nurses interviewed and 64% of the nurses in the survey cited it as part of what sustains them. It is like a mantra whose repetition allays doubt. It is a code which encapsulates the difficulties under which they work and the goals they seek. Using this code, they constitute a world of meanings (Good 1988). They do not aspire to greatness; their aim is to do what they can, and that will be limited by the constraints of the medical system, their own capacities, and their patients' responses.

Yet they know that they are having an impact, even if it's only on a small group of patients or within one hospital. Sixty eight percent (68%) of the nurses interviewed and 53% of those surveyed

said that knowing that they are helping others was what kept them caring for HIV infected patients. For nurses in the municipal hospital system, where resources are limited and the patients have multiple problems, the knowledge that if they weren't doing what they are doing, these patients would be in even direr straits, sustains and rewards them. As Gretchen S., who worked in a busy and something chaotic municipal clinic, said:

Every patient who comes through that door is not someone with nothing else to do but go to the hospital. People here are for the most part extremely ill, in terrible circumstances. We have to pick up the pieces so to speak. I stay here, I guess, because I feel needed here more than at another hospital. Here there's such a glaring need, and luckily I'm a member of a team of people who are very dedicated and who make working a joy, even though the work's very difficult.

In addition to the pleasure of helping another, there is the attraction, for many of these nurses, of coming face to face with existential mysteries. As one nurse said, "there are universal themes, there are commonalities in all of this." Nursing HIV infected patients puts caregivers in touch with fundamental questions of human existence, particularly how to live in a world where death is inevitable.

For many of these nurses, therefore, HIV nursing is an opportunity to consider, in their work, what living and dying mean. For some, part of the satisfaction of HIV care is helping patients face death and facing the possibility of death themselves. Lore H., who was about to return to bedside nursing of HIV infected patients after

time out in administration, said:

One of the things that I think sets people who work in AIDS apart, I know it sets me apart, I can only imagine that it sets other people apart, is, if you talk with people who work in business or you talk with people who work in almost any field, and you talk about life being short, that old cliché, and you talk about what's important and why things are important and stuff, their work is very shallow and doesn't have as much meaning.

Caring for HIV infected patients also often puts nurses in touch with much that is admirable in people's lives, particularly in individual's and families' response to the illness. This is part of the personal connection with patients which 72% of the nurses interviewed and 73% of those surveyed said was one of the satisfactions of this work. In this there are similarities to caring for cancer patients twenty years ago when there was little to be done for patients. Then as now, the heroism some patients and families exhibited could be an inspiration to their caregivers. As Carey M. said of her observations of women and children with HIV disease:

The poignancy of some of the families and the courage I see demonstrated is remarkable, and I suppose that being allowed to be close to that is to be privileged. When I talk about it, I'm very close to tears.

Taking care of HIV infected patients lets nurses get close to both some of the worst and some of the best that human beings are capable of. Some HIV infected patients display everything that is despicable in human behavior; others are truly heroic. Nurses taking

care of mothers and children are particularly struck by the fortitude and endurance they witness. The nurse quoted above, who was involved with perinatal studies of HIV disease transmission, said of one of her patients:

I think of the young woman of thirty who was already blind from a genetic disorder, and she has this kid, she just recently died, but I was just totally amazed to her ability to cope. I think the thing that strikes me most about the patients I work with is their incredible ability to live with this. Their courage astounds me. I think of another patient who is very sick and weak and thin, she's repeatedly getting different things, and it's very sad to see. But she's also one of the people who's partaken of everything around her. She got help from GMHC [Gay Men's Health Crisis], she got a buddy, she got everything she could get as far as social services, she got herself the best medical treatment she could, she got herself into Sloan Kettering [New York City's preeminent hospital for cancer patients], and she's made arrangements for her daughter's care. Her family's coming up to get to know the little girl so that when she does die, her daughter will know them.

Some patients change their lives all around when they become ill, proving to their nurses that transformation is possible. Alice D. commented:

I've heard people say so many times, "Now that I'm dying, my life has never been so good," The quality of their life, the way they've kind of reconstructed their whole way of looking

at things has changed, and it's really increased their inner peace, their strength, their spirituality, their way of coping with things. I think it's interesting that faced with such a grim prognosis, people can still find some kind of meaning to their lives, and still maintain a positive attitude. They decide who their real friends are, the quality of the time they spend with them becomes so much more meaningful. So it's not all bad, so it's not all grim. I've gotten a lot of very positive things from them. I suppose it's with any terminal disease, you learn not to take anything off of anybody. You learn not to be concerned with the petty things of life and you really find out what your priorities are.

In this scenario, the patient becomes the teacher. Just as the anthropologist learns from the people under scrutiny, so do nurses learn from their patients. Some of the teaching is about the right way to provide humane clinical care. As Stephanie C. said:

I had a wonderful patient who was a lovely man; I'll never forget him. I learned so much from him. He had a nice death, he did not want to be intubated. He had cancer, KS, and it went to his lungs; he was struggling to breathe, but he didn't want to be resuscitated. So what we did was set up morphine shots around the clock so that he would be sedated. His family was there and now what I have is this imprint of ____ in my mind, and when I see a patient who has a similar problem, I then can take that and put it right into practice.

What taking care of HIV infected patients does for many of these nurses is enlarge their own understanding of human problems

and increase the number of different responses they can offer their patients. Because the questions patients ask frequently have no easy answers, this process can become a collaborative one, in which nurses and patients approach problems together. As Stephanie C. described the process:

For example, a young woman who is minding her own business, who is not taking drugs, who is not doing anything, and all of a sudden, she gets the news that she's HIV+. Then comes a series of infections and this downward slippery slope, and she might say to me, "I know I'm going to die, how can I do this with as much dignity and grace as possible?" And I don't know, I don't know. I'm using the inventory I have as a person, and there are times when I feel that I don't have enough to be a resource to these women. What I do in those instances is tell the women that I'm here for you, we'll explore this thing together, and as much as I can, I won't leave you. We'll solve the problems together, and we'll do as much as we can together. And whatever we learn together, we will teach other women.

Thus individual experience is preserved and incorporated into knowledge that is available to others. Just as anthropologists organize what they have learned in the field and present it to their colleagues, so do nurses share their knowledge with other health care workers and with their own patients. Nursing becomes something more than analyzing a patient's condition and applying the appropriate remedy. It becomes a creative process between the nurse and patient.

Nurses learn from patients in HIV care and patients learn from

nurses, not only about their disease and how to treat it, but about human relations and tolerance. Fifty two percent (52%) of the nurses interviewed and 60% of those surveyed said that comforting patients and families was one of the challenges they faced. In order to do this nursing practitioners have to be open and tolerant, and one of the rewards of this nursing is to see families and other personnel develop similar attitudes. George N. said:

I like to see people have time to resolve some of their internal and external problems, to see families accept certain things. I'm not saying it's something they want to accept, but it's something that society as a whole doesn't want to accept. For some families to come to the realization that "Yes, this is the person's lifestyle, and we're going to accept that," and "Yes, this may or may not have led to their death, but they're mine t regardless of what I think about this," This has some satisfaction. For instance, you may get a substance abuser who has been completely disentangled from his family for many, many years, and in the course of his exploits may have produced two or three children, but he's completely alone. You will find that there are children and loved ones, and sometimes you're able to get a family some assistance so that the children can come to say goodbye. You work everything out, the legal paperwork, and the children say goodbye, and that's satisfaction, that he could live long enough to have that.

Having a real impact on patient's lives is one of the satisfactions these nurses report. And part of the reason nurses

enjoy this work is that they can have an impact. There is considerable scope here for nurses' initiative and intervention. With HIV nursing the sphere of action and involvement is much wider than with other kinds of nursing. All sorts of problems have to be addressed and all sorts of skills are needed. Nurses are fully engaged.

For many, it becomes an opportunity to be the kind of nurse they always wanted to be. Seventy percent (70%) of the nurses interviewed and 64% of those surveyed said HIV care gave them the opportunity to use every kind of nursing skill. As Emma J. said:

I've just moved to a clinician position, but I'm still there to help with morning care if they bog down, I can pitch in and give a bath or change a bed, or whatever, but my primary focus is different. What they really want is for me to spend more time with the people in scatter [not in dedicated AIDS unit] beds, give them more emotional support. I'm very free. If I go in and somebody is having a really bad day, I can sit there for a good long time. Nobody is going to pressure me. That's a gift. And it's all the things that you ever wanted to do, that you were told good nurses did, but you never had time to do.

HIV care allows these nurses to be the nurse they always wanted to be. The lower nurse/patient ratio prevailing in most dedicated HIV units gives nurses the time to get to know their patients. The fact that other healthcare providers are not competing for these patients gives nurses a freer hand and a chance to organize care on nursing principles. Because of the nature of the illness, the

patient populations, whether in hospital or not, need the comprehensive involvement which these nurses see as key to their own experience of nursing.

Nursing is central to the management of HIV disease; thus in HIV care nurses find their skills, their attitudes, and their performance validated and approved. This contrasts nicely with the wholesale denigration of their profession which occurred during the 1970s, partly as a consequence of the women's movement, when traditional female occupations, such as nursing and teaching, lost status and respect.

In addition, being the nurse they always wanted to be holds numerous personal rewards for these nurses. They enjoy the gratitude of their patients. They know they are doing something which is important to another person and that gives them pleasure. They help their patients achieve a better understanding of how to make the most of life, and in the transformations which they witness and support, nurses share in their patients' courage and fortitude.

With their patients they face the griefs and joys attendant on mortality, and they grow themselves through their involvement with others who are growing. Seventy four percent (74%) of the nurses interviewed and 64% of those surveyed cited personal growth as one of the reasons they stayed with HIV care. Along with their patients, they can experience rebirth and renewal. They move along with their patients from one discovery to another and as their companions and their facilitators, they participate in their patients' progress.

That progress is towards a more profound understanding of the human condition, and what they learn on this journey they bring to

other patients. They share with others the knowledge they have gained through their acute and sympathetic observation of and involvement with their patients.

Thus the narratives these nurses retain and the ones they want to share are about the successes they experience in caring for HIV infected patients, because it is in these successes that they experience growth and renewal. Essential to this success is the personal connection they establish with their patients, because their successes are dependent on the relationship of trust and respect which they create with the patient. Only then will the patient let the nurse guide the encounter. If such a relationship is not possible, and some patients are not interested in such a link, the nurse continues to provide the care but the episodes of interaction, for the nurse, lack the depth and meaning which, with other patients, make nursing so enjoyable.

Comparison of Interview and Survey Responses

Table 5

Question #3: What are the satisfactions?

Response:	N	%
1. teaching and counseling		
interview	2 6	52 %
survey	4 3	76 %
2. involvement in important work		
interview	3 4	68 %
survey	4 2	75 %
3. establishing a personal connection with patients		
interview	3 6	72 %
survey	4 1	73 %
4. being able to use every kind of nursing skill		
interview	3 5	70 %
survey	3 6	64 %
5. meeting the challenge of clinical care		
interview	3 0	60 %
survey	3 2	57 %
6. working with like-minded colleagues		
interview	1 0	20 %
survey	2 7	48 %

XIII Self-Knowledge

The nurses in this study study their patients, and in so doing, they learn about themselves, because this kind of nursing requires that its practitioners monitor their own reactions as well as their patient's. In HIV care many accepted attitudes and assumptions become subject to scrutiny, and so in order to do this work nurses must be aware of and willing to examine their assumptions about social life, sexuality, drug use and other issues usually concealed behind conventional thought and behavior.

Contact with HIV infected patients disturbs nurses' equilibrium. This often leads to change and development. Just as fieldworkers report that they have learned a great deal about themselves through their experiences (Norbeck 1970), so do these nurses. Seventy four (74%) of nurses interviewed and 64% of those surveyed cited personal growth as a reason for continuing in HIV infected care. As Stephanie C. said, "Patients grow with you and you grow with them."

HIV care can be an opportunity for personal development. When cultural expectations are disturbed, insightful self-examination can be the route back to equilibrium. As Boddy has commented about participation in 'zar' rites, "fresh interpretations of everyday realities ... help to develop adepts' consciousness of themselves" (Boddy 1989:348). Having to confront that which up to now was hidden or denied, such as racial, ethnic or sexual differences, makes nurses rethink their social world. Nora J. said:

Have I grown in this work? Definitely. I've obtained a wealth of knowledge, all sorts of knowledge. From going to various

conferences, I've met people from all over the world and the U.S., which has definitely increased my growth and knowledge. I've worked with people from all different populations, and it's been interesting psychologically and emotionally, particularly in working with prison populations. I've learned a lot about areas I normally wouldn't have learned about, about patients' families, about how they want to care for the patient at home, about social services. I know more about human nature and what goes on with people, whether they're in a higher economic class or a lower one.

This process can force nurses to develop technical skills they might not have needed in another kind of nursing. Chris T., whose position as an AIDS advocate brought her into contact with high-level government officials, said:

I think my experience with AIDS and the jobs that I've had have allowed me to advance and develop in areas that I know I otherwise wouldn't have gotten into, for example, public speaking. I'm not the best public speaker, but I can do it, and five or seven years ago, I would never have thought I could. I've done a fair amount of it now. Getting involved with computers and research and data stuff, that's also been a part of it. I'm not expert in that but it's a learning thing, something to add to your skills. Along the way, with AIDS, I've been pulled and pushed to advance some of my skills, like writing and management skills.

Anthropologists also feel stretched in the field. They may have to eat strange food, tolerate more or less human contact than they're

used to, participate in uncomfortable activities, adjust their behavior to other's requirements, and, quite often, develop capacities they didn't know they had. Many anthropologists come back from the field feeling that they have gone through a rite of passage.

Similarly, many nurses I interviewed said that taking care of HIV infected patients changed them. On a day-to-day level, they are less concerned with trivialities. One nurse said he was amazed when his friends became upset by such things as being served incorrectly at a restaurant. In the face of HIV infection, how can these things matter? As one nurse wrote in response to the survey:

For a long time I maintained that it [nursing HIV patients] had little or no effect on me except to make me more sensitive to issues of death and dying. I now realize that indeed, there have been some very long term effects. I appreciate family and friends more than I used to. I have also ended an unsatisfactory marriage because I realize that life and time are too precious to waste. I don't believe in the hereafter; therefore I think that this life should be lived to the fullest.

Dealing with AIDS has made me more appreciative of life. I try to pass this appreciation on to my family, friends, and particularly my children.

Gretchen S. agreed:

I do think that there's been a lot of personal growth in terms of this idea of my work, my clinical work being a creative thing, and that somehow I've got more of a focus on today. This is what we've got. I'm not a religious person, but this is what we have here. And this should be good. We should make

it good because we don't know what it's going to be.

Sometimes it's hard to remember, but it's really become a philosophy that I've tried to keep in mind as I go through the day. If it's sunny out, just be glad it's sunny out. If it rains, look at something else, look at shapes, look at figures. I'm not going to take my pleasures in ten years. Also I want my interactions [with other people] to be real; I don't really have time for most mundane chit chat. It doesn't mean that I can't laugh though; I laugh a lot.

The one issue which nurses caring for HIV infected patients have to face and accept is the issue of their own mortality. In order to care for HIV infected patients, nurses must understand their own feelings about death, their own and others. Accepting death, as a part of life, is central to HIV care. As Carey M. said:

The biggest issue is confronting my own mortality. There's no escaping that. That comes up daily, several times a day, with patients and with families. I guess it's made me get in touch with my philosophical self.

Nora J. put it rather differently. Turning Freud upside down, she said, "In order to do this work you have to be convinced of your own immortality." And indeed almost all the nurses I interviewed believed that there was something after death. Some believed in the Christian traditions of heaven and hell, but the majority embraced vaguer images of another life. Sixty nine percent (69%) of those surveyed thought of death as a passing to another kind of existence. Bette V. said:

I guess my own feeling is that there is a continuum of

experience that includes life and death, and so it's a sort of spiral. That doesn't mean that the focus isn't on living, it's very important to get whatever you can, whatever experiences you can out of your life, rather than focus on what's coming afterwards, but to recognize that there will be something afterwards.

Carey M. commented:

I'm not sure there's a conventional heaven, but I think there is something after death. I feel it when people say to me, "Oh, I wish I'd said that to my mother or sister or whoever, my loved one before he or she died," and I say, "that's all right, you're saying it now and he or she knows it." My way of getting through someone's death is to say, "I bet you're somewhere;" I talk to them. I don't have a clear idea of what it's like, but I believe that there is some collective, unconscious something there.

Whatever conclusions these nurses come to, what is important is that HIV work encourages them to think about personal mortality and to come to some peace with the prospect of dying. Much as many of their patients do, they discover, through their involvement with HIV disease, what some of their real beliefs about the conundrums of human life truly are. The ability of these nurses to do this hinges on their openness, not only to their patients, but to themselves. They have to face within themselves the same fears which their patients face, and they have to resolve them, as many of their patients resolve them, in order to continue doing this work.

As these nurses move towards greater self-knowledge, they

find confirmation of who they think they are or hope to be in the reflections others mirror back to them. They see themselves in the images others have of them, and the first image reflected back to them is from their patients. Sometimes they are surprised at what their patients see. Toby B. was startled by how she appeared to one of her patients:

His lover had been here, and this patient used to come in to visit. They were lovely. I used to talk to them and joke with them, but he was always very businesslike, and he did a lot of business on the phone while he was visiting his lover. Lo and behold, he was admitted a few weeks ago. I didn't go in to see him right away, and when I did, he turned around and he said, "Oh, there you are. I wondered when you'd come in. I would like to know if you would like to work for me." He was an executive with an AIDS research organization, and he said, "You have the most amazing ability to get a group to work together and be just as nice and supportive as you are. How do you do that?" I was almost thrown back out of the room. I said, "What? I didn't even think you'd remember me." He said, "Of course I remember you," and every time someone would walk into the room, he'd say I was wonderful.

Nurses' families surprise them too. Several nurses said that their families had become active in HIV education and volunteer efforts for AIDS programs after initial doubt about their childrens' choice of work. Toby B. went on to say:

My mother and father have always been proud of me, but now my mother's done AIDS education to her office staff. It's a

"my daughter says" type of thing. My father also. But the one I was most surprised about was my brother. I was just amazed at how much my brother talked about what I did. I always thought he didn't. He never said he wasn't proud of me or anything, but now I meet people he works with and they say, "Oh you're the one who works in the AIDS unit. Your brother's told me about you."

There has been a change in the past year or so, according to some of the nurses I interviewed, in the public's perception of health care workers who are involved in HIV care. Whereas earlier nearly everyone connected with the disease, whether patient or caregiver, was avoided and derided, now the feeling is frequently that those who choose to do this work are admirable. This naturally supports these nurses' own image of what they are doing. As Agnes S. said, "I am adventurous, I am courageous. I am a pioneer." By tackling the unfamiliar, nurses discover new capacities within themselves.

For some nurses the route to HIV nursing has been through self-discovery, a self-discovery fostered by a maturing understanding of what nursing is or can be. As Stephanie C., who has more than 20+ years of nursing experience, described the process:

When I was a young nurse, the thing that I used to think was a requisite for job satisfaction was the level of action, what we called the blood and guts. The surgeons, the ICU nurses, they were the most admired. I was a nurse anesthetist for seven years and I loved that. I had a lot of autonomy at the head of the table. It became very technical, more and more instrumentation. The patient was asleep, there was no patient

relationship except before and after anesthesia, so I found that what was most satisfying for me was the technical expertise of the job. Then gradually as I matured, it got to be routine and repetitious and mechanical. Then my child was diagnosed with a serious disease, and we were exposed to the medical system from the other side, and I saw how important nurses were to the family and to the patient. They really made the difference in the experience of the illness. They didn't change the diagnosis, but it made a difference what nurse was on duty when we went for treatments. There was a particular nurse who was very talented and who really gave of herself, and when she came through the door, my husband and my child and I experienced whatever happened that day in a different way. And that said to me, "Wow, that's what I want to do now," and I went back to school. I went back oriented to new his became very exciting because I discovered I was very good at it.

HIV work can be a setting within which nurses continue to learn what they do well and how that can help the patient.

Stephanie C. continued:

I've learned that I'm very good at conveying the hope in the situation and enabling people to see that each moment is precious, that this moment, living right now, today, is precious. I try to get people to slow down time, to enjoy each other, to go for a walk. I'm very enthusiastic about life and I think I'm able to convey this. At least patients tell me that that's what they get from me. They get hope from me but a

realistic hope.

She went on to say:

I've learned I'm very good at translating what the doctor said into concrete information that the patient can use, into something that means something to them in their lives. When a doctor comes in and says, "Gee, your numbers look good. We'll discharge you tomorrow," the patient needs to know what that means. What I do is tell the family, "she's going home tomorrow but she's going to be very weak. She'll slowly need building up and you do that by good food, lots of rest, let her listen to music or whatever she likes to do." And then I ask the patient, "What do you like to do?" and they'll say, "Oh, I like to draw or I like to play with my grandchild or whatever." I enjoy getting engaged with the patient and maintaining that support system for them which goes on even after they leave the hospital.

Self-knowledge thus becomes a therapeutic tool. "Knowing who you are," John N. said, "means knowing what you have that can help others. This is what I am and this is what I can do for you."

Of course, part of learning about oneself includes learning what one cannot do. This is valuable information too and can promote collaboration and collegiality with other members of the health care team. Nurses of HIV infected patients have to work within the framework of their own and their patients' capabilities and they accept both their own and their patients' limitations. Stephanie C. said of herself:

There are some patients I've learned I can't deal with very

well and some others can. That's why one's coworkers are so important. For example, ____ is much less judgmental than I am. He's very important to me because I know I can always go to him and say, "I'm having trouble with this patient," and he'll help out. I have trouble with substance abusers and alcoholics. Up to a point I'm able to work with them. In general I'm able to work with them. My trouble starts when I see people using drugs and beating their children, beating their husbands or wives, not keeping their clinic appointments, and then coming back and being very demanding, and insisting on getting seen ahead of other patients. I have a lot of trouble with that. I feel that we're working so hard and doing such a good job here, and when these people come in, and they use the most terrible language, very abusive language, and they come right into the clinic and say, "I know I missed my clinic appointment three months ago but I have to be seen right now because I'm sick." And you look at them, and you see the fresh tracks on their arms, and you know they've been stealing and shooting up. At that point I get impatient. ____ never does. And I know that when I feel this coming, all I have to do is drop back to the second line; ____ takes over. I can do the same thing for him. You learn where you need support and how and where to find it. I've learned my limitations.

In this process of recognition, reflection and response between patient and caregiver, the nurses I interviewed become clearer to themselves and to others. What was perhaps only known to

themselves, or known as a latent power or attribute, becomes visible to all. As Watts and Williams remark, "It is a psychological truism that self awareness and self realisation are achieved in the context of personal relationships" (1988:103). It may even be that self awareness and self realisation are not possible outside relations with others. And as Malson says:

Before his encounter with others, man is nothing but a notional quantity as thin and insubstantial as mist. To acquire his substance, he requires a milieu - the presence of others. (1972:10)

Nursing almost always includes personal relationships and so offers its practitioners a venue conducive to self actualization. In others' reaction to them, the nurses in this study frequently find the approval which supports their desire to act in ways consistent with their principles. Through their patients' responses, in what families say, in what doctors do, nurses see themselves as others see them, and what they see pleases them. They see people who are intelligent and knowledgeable, people who are strong, people who are active, people who are virtuous. Who they are develops through their involvement in HIV nursing. This is dynamic learning. As the disease changes and as the patients change, nurses learn new things about the disease, about patients, and about themselves.

HIV care is thus not for those who are unsure of themselves, who have doubts about what they are or might be, who need to buttress their sense of self with denial. In order to be open to others, a practitioner must be self-aware and self-accepting, so that the deficiencies of other people become a bond rather than a barrier.

Those who are open to what people at the margins can teach them
will be attracted to HIV care.

XIV Nursing Consciousness and Time

The knowledge these nurses develop, about themselves and their patients, is achieved through human relationships, and as such, is a kind of knowledge disdained by the prevailing ideology of the American medical system. The American medical system is founded on physical science and the use of the scientific method. It relies on empirically demonstrable effects, and it fosters an 'objective' stance. American medicine believes that each disease has a known etiology and a natural history which plays itself out the same way in each individual patient. Treatment is therefore the same for every patient. The goal is to control and eliminate the source of the disease using chemical drugs and/or surgery (Payer 1988; Starr 1982).

Nursing seeks rather to mobilize the patient's own resources in response to disease. Part of that mobilization will be medical interventions, but only part. Mobilization will also depend on the nurse's ability to elicit and sustain health-enhancing behavior from the patient. Nurses seek to understand and use what they know to foster a process which occurs within the patient. It is not imposed from outside. Thus nurses think along with patients rather than thinking for them. They listen; they believe. As Marcia B. said about 'difficult' IVDU patients:

I think it usually boils down to if the patient tells you something, you can't discount what they're saying to you. The drug abuser, the AIDS patient who is going crazy, they're not just screaming because of their personality, it's their underlying need, that perhaps led them to use drugs.

A nurse, without being made a fool of, has to believe her patients. She is skeptical at the patient's peril.

In her posture towards her patients, the nurse again resembles the fieldworker who accepts what his informants tell him, then gradually over time, refines his understanding. Nursing and anthropology both operate within a web of relationships and they succeed through the efficacy of relationships. This is why, when medicine has nothing more to offer, there is still a great deal for nursing to do. Some would even say that nursing continues after death, as the nurse tends to the last duties to the body.

It is to the patient's body and through the patient's body that the nurse promotes healing, and it is through ministrations to the body that nurses' consciousness is developed. It is a consciousness embedded in and drawing strength from natural life. It does not seek to control and direct natural phenomena through force; it seeks to influence natural phenomena through collaboration and persuasion.

For nurses, the natural world can help, because nursing accepts humanity's animality. American culture, with its well-known insistence on personal cleanliness, strives to forget that human beings produce fluids and products as an accompaniment to life (Miner 1956; Perin 1988). But nurses learn to overcome their repugnance to bodily fluids, a repugnance ingrained in American society and eminently expressed in the stigma attached to HIV disease.

Because nursing accepts the conditions of human life, nurses see the individual as always and everywhere connected to others and the nurse connected to the patient. As Stephanie C. said:

Many nurses can't articulate it but it's there. It's a connectedness within which there's trust, and there's freedom to be who you are. It's non-judgmental. Meaning is attained within this human experience of connection. It is not superimposed or divorced from it.

Human beings, for the majority of the nurses I interviewed, are engaged in the great and recurring drama of human life in which individuals are born, they live, and then they die. It is a cycle of birth to death through which everyone passes; it is also a cycle which never ends, and in which in some way everyone who ever lived is still included.

This is a conception of time which incorporates the past and the future into the present. Eliade (1954) calls it the "continuous present" or "mythical time" in which the here and now is inseparable from the past and the future . Such a conception recognizes inevitabilities inherent in human life and accepts them as inescapable conditions. It does not try to avoid these conditions; it sees them as the mark of humanity. And it is the fact that all human beings experience these events which is the basis for human connection and identification with others. As Roberta M., who worked in an elite hospital, said:

Nobody goes through life completely free of pain, sorrow, hurt, or any of the horrible feelings. Everybody in their life experiences some horrible, painful situations. I think that this has been reaffirmed since I worked on this unit because I see such horrible, horrible things that nobody deserves. Nobody should suffer like these people do.

In this conception of life, pain and sorrow know no boundaries.

They come to all. Everyone, at some point in their lives, will be vulnerable, unable to care for themselves, and dependent on others. This is an understanding central to these nurses' consciousness of human life. It underlies Alice D.'s decision to teach. She said:

Someday I'm going to be sick, and I want a competent, caring person taking care of me, and that's one of the reasons I'm in teaching. I want to educate the next generation for the next generation who are going to be sick.

Rich and poor, black and white, men and women, everyone who lives will know what suffering is. As Gloria R. said:

We all have our issues, including the people who are so called "privileged". They may have problems that may not be financial but are very relevant. For example, gay men who have lived in the closet but who had to come out and tell, or perhaps chose to tell their parents, and had to talk to their parents and tell them for the first time that they were gay and that they have AIDS. Or they've had multiple deaths among their friends, all their friends are dying or have died, or you know two partners, two lovers both have AIDS, one is going, the other one is helping out and knows that he will go eventually too. That's devastating.

It is this understanding that we all suffer because we are all human which draws the nurse to the patient and which defines the 'patient' as a human being in need of care. The category of 'patient' includes everyone. As Nora J. said:

No matter how big and strong you are, how many muscles you have, you still have to worry about how your family is going

to accept this. Are you going to lose your significant other?
Are you going to lose your friends? Am I going to be alone?
Am I going to be an outcast? Who is going to take care of me?
No matter what walk of life they come from, they are all going
through the same thing.

It is this understanding which is expressed in the gestures of human concern which are the hallmarks of this kind of nursing practice: the outstretched hand, the physical contact, the solace and comfort given through the body.

Accepting the inevitabilities of human life may be part of these nurses' personal growth and development, but it is not easy. As Lore H. said about a dying patient:

I don't deal with it so well. I try to work as hard as I can, that's really what I'm doing, but I often feel very bad. For example, I have one woman here now, she was just admitted, but I had seen her in clinic, one of the physicians referred her to me. She's end-stage. She's in a wheelchair. She's blind. She has a child who has AIDS. She came in yesterday and I hardly recognized her. And this morning at 8 o'clock, I ran into her room to see her. I'm obsessed with her, I'm not denying that, I just go and see how she's doing and get tearful and feel awful that this is the end. I wish I could say that I don't, that I had these wonderful coping mechanisms in place. No, no, it's terrible, it's terrible.

Accepting inevitability means accepting pain and grief and terror. But by accepting it, a source of community is discovered and so within that acceptance there appears a defense against the pain

and terror. Against the background of death and sorrow, the practice of the nurses I interviewed establishes that there are other certainties which can be created and sustained by human beings. Human beings live and die, over that there is no choice, but the manner of their life and death is something chosen. Nursing practice, for these nurses, becomes a continual enactment and reenactment of this truth.

The practice these nurses espouse combines two views of man, the first that each individual plays out a story common to all men, and the second that each individual can affect how that story is experienced. It thus combines two notions: the first that each individual is important and that his or her particular history has meaning, and the second that there is an eternal flow of life, expressed as the journey from birth to death, in which all men participate no matter what their individual experiences. For the human race, what is ultimately important is the cycle of birth to death, but recognition of this universal truth results, not in a nihilistic rejection of life, but in a realization of its preciousness and value for the individual.

For the nurses I interviewed, the preciousness of human life is expressed in the care they give their patients. In a world where much is unstable and where values shift, nursing says that people should be protected and that the fullest experience of living is found in caring relationships with other human beings.

These nurses' insistence on taking care of the whole person is an insistence that life is a unitary experience, that we feel with our bodies and our minds, that we think with our bodies and our

feelings, that we act with our minds and our feelings. Human experience is all of these things together. The meaning of human experiences comes from what the body is doing and the body does what it does because the mind with feelings engaged permeates the body's actions. For the nurses I interviewed, nursing gives them the opportunity to experience the unity of what Western culture has separated for analytic purposes into separate categories, the sensory realm, the rational, and the emotional. As Jacques Maquet says: "Intellectuality and affectivity, volition and action are easily distinguishable concepts in our ordinary communication" (1986:166). These are the watertight categories used in analytical thought. In nursing, however, the subjective and objective are used together. Feelings, thought and action are intertwined. As Stephanie C. said, "It's not a case of either/or. We have to have both."

In caring for the sick, the nurses I interviewed experience and create an encounter which exemplifies these concepts and which becomes an expression of these truths. Each episode with a patient is an opportunity to make these values real. All of a nurse's faculties are needed. An active intelligence and disciplined emotions are brought to bear on sensory experience. In contact with a patient, these nurses can establish a relationship in which collaboration is more important than control, where self-assertion is restrained, but in which selfhood, of both the nurse and the patient, can be experienced fully. One nurse commented: "It's a privilege to be there." For both patient and nurse, as for anthropologist and 'native', it can be a mutually rewarding experience.

This kind of experience does not occur in every nursing

encounter and nurses do not expect that it will. But nurses can frame the relationship, much as an anthropologist sets up a field interview. The nurse is in charge; she can resist being drawn into the patient's perspective and can refuse or cut short an episode which is not going as she wants. She can come back later and try again, when the patient seems more amenable. In this way she maintains her independence at the same time that she remains open and accessible to the patient. Thus, even in the most beleaguered situations, there is always the possibility of an encounter in which patient and nurse agree to act together, recognizing and respecting each other's humanity.

When nursing is conducted in this fashion, it is as though many of the walls, psychic and social, preventing contact between individuals are breached or erased. The constraints of ordinary human life disappear and a freer, more generous mode of human interaction becomes possible. This is experienced as freedom. It is a freedom to establish a relationship with another human being unrestrained by worldly considerations and functional rationality. In such a relationship, these nurses find the freedom to be themselves and to heal their patients. As Chris T. said about caring for IV drug users:

If you're decent to them, they're very, very grateful, and you can interact in a way that's a little freer. I don't know how to describe it exactly. They're a tough group and they don't tolerate any bullshit. You can't run anything by them. But, on the other hand, you can be very frank with them, and they appreciate some of that stuff that other people might find

offensive or something. I don't know how to describe it exactly. You have to work with a different attitude about your goals and your aims and your measure of success.

The freedom found in caring for HIV infected patients comes from a paradoxical acceptance of limitation. It is an acceptance of the human condition, that there is good and bad, hope and despair, laughter and tears. Human life is composed of a host of opposites: courage and cowardice, kindness and contempt, trust and betrayal. As Hubert Benoit states, "in refusing to accept limitations, man [sic] deprives himself of the impression of liberty which he feels when he is within accepted constraints" (1955:154). The nurses I interviewed accept the limitations inherent in human life. This enables them to focus on that which is not finite, the capacity to connect with other human beings.

XV Nursing as a Moral Undertaking

As documented in the American Nurses' Association Code of Ethics, nurses are not allowed to pick and choose their patients. They must care for the patients assigned to them. Anyone who is ill is worthy of attention, and that attention should be the same whether the sick person is rich or poor, white or black, male or female, or exhibiting any other social or physical attribute. Whoever comes to the unit, or registers for home care, or signs up at the clinic is to be treated and to be treated to the same standard. As Alice D. explained:

The National League for Nursing has come out with guidelines that say that this [learning about AIDS] should be part of nursing education, because now you just can't say, "well, I won't work on an AIDS unit," because AIDS patients are going to be all over. They're everywhere and you're not going to be able to refuse, even if it were ethically correct, which it is not. Nurses are going to have to come to grips with this. It's slow going but it's coming. Nurses are doing better than doctors. Maybe it's because we're not given as much choice. We're not private practitioners. Doctors can, regardless of their pronouncements, they can pick and choose. They can just say, "I'm not really qualified to take care of AIDS patients. You're really better off going to a doctor who is an AIDS specialist." They have an out. Nurses don't have that out.

In caring for HIV infected patients, the nurses in this study were honoring the moral principles of their profession. Behind the focus and interest on clinical issues, which are foremost in nurses'

own discussions of the disease, there lies a code of ethics which directs and informs practice. This ANA [American Nurses' Association] code has been clearly articulated in the statements of the Association of Nurses in AIDS Care, a professional organization dedicated to the promotion of the health and welfare of people infected with HIV disease. The Association's statement on nurses' Duty to Care says that "all professional nurses have a responsibility to deliver care to HIV infected individuals regardless of risk factor, lifestyle, racial or ethnic group."

The nurses I interviewed believe in this code and practice with this code in mind. Sixty six percent (66%) described themselves as committed to providing healthcare for all. So do the nurses in the survey; 64% described themselves as working to provide healthcare for all. They are committed professionals whose nursing practice is more than a technical task. They are making a moral statement.

None of the nurses I interviewed believed that nurses should be able to pick and choose their patients. Such a stance does not mean that these nurses would force workers to care for HIV infected patients, but it does mean that a hospital nurse or a home care nurse must accept whichever patients are on their roster. As Robin M. said:

You cannot choose. I don't think you can. I don't know exactly how medicine or surgery work, but I know for nurses, you cannot refuse an assignment. And how do I feel about it? I think it's wonderful. Because if you choose to work in this, many years ago you had other diseases that were easily transmitted and people used to work with them. You don't take risks, and you're very very careful. But I don't think

that anyone of us should refuse to take care of anyone, even if you don't agree with the person's lifestyle. That is not the point.

In choosing HIV care, these nurses are putting their bodies, their minds, and their hearts behind their beliefs. They are acting according to the highest ideals of nursing. And they are acting freely; they all have had opportunities, because of their education and experience, to take positions which would not bring them into such constant contact with HIV disease.

Because other health professionals they came in contact with do not always agree with them, these nurses not infrequently find themselves at odds with workers operating from a different moral framework. As Nina H., who worked in a municipal hospital, said:

It's a real problem, like finding a patient in full distress, the doctor hasn't been up there in a few days, and you know he's not coming. We had a patient who left our unit, but had to stay in the hospital because he didn't have a place to go, so they put him on the service where they're supposed to be given supportive care, and he had to come back to us because he became acutely ill. This is someone who was in a hospital! He was under the care of a physician. He became dehydrated. That should never happen in a hospital. He also had thrush, it was all up his nose; he looked like a rabid dog his thrush was so bad. That was obscene as far as I'm concerned. I blame the nursing staff almost as much as the doctors. I have never seen thrush like that. He couldn't open his mouth. And it's so easily treated. There's a wafer, and if that doesn't work,

there's a liquid, like a swish and swallow. Sometimes that doesn't work and you need a systemic, which we gave this man, and within a week, he was OK. But, as I say, nobody listens to me.

Because of the hierarchy within the American medical system, and because of the traditional relationship of nurses to doctors in this system, nurses often have to be extremely persevering in order to get HIV infected patients the proper care, particularly in municipal hospitals. Nina H. went on to say:

I will walk into rooms, and I have found patients seizing, and they haven't drawn bloods for two or three weeks. Then, if you want to go to a specialist, if there's a special problem, we've just been told recently to stop doing that, to go instead to the primary physician and ask him to call in the specialist, like a neurologist. Most of the time the primary physician just tells us, "Yeah, yeah, yeah," and they don't take any action.

In the face of such reactions, it is hard not to give up, but these nurses don't. They stay in there. They make the calls. They keep after it. Nina H. described how she pursued one patient's doctor:

I don't pretend to be able to diagnose everything, but some things are very obvious. One patient I had to call the doctor and say the potassium was really high. She said, "Oh?" so I told her, "Why don't you do this, this and this"; "Oh, OK," she said. But three days later I went back, and she hadn't looked at the results, so I had to call her again.

Another nurse said, somewhat wistfully, "It's a battle. If you're not really assertive, you're not going to survive." Another commented

that she always seemed to have more energy to keep pushing for the patients on Mondays; by Friday she was less apt to keep after things.

Some nurses find it hard to maintain their own hope and optimism in the face of their patients' experience. It is a struggle to accept the limitations of what can be done. Fifty four percent (54%) of the nurses interviewed and 35% of those surveyed said that working within the limits of care was a challenge. As Toby B. said:

[At the beginning] I would want to do more and more and more, and I think just the realization that you can't do more took a while. Not that you shouldn't try, but at some point, there are going to be many people for whom you can't do more.

Actually just getting what can be done done is hard work. Forty four percent (44%) of the nurses I interviewed and 28% of those surveyed said that persevering through difficulties and failure was something they had to work on. Gretchen S. explained what she came up against in a municipal hospital:

Take, for example, the CAT scan. They [the patients] have two choices. They can go to the emergency room, and they can wait in line to get a bed, which would take two or three days, so they can get a CAT scan. Or they could try to go over and get an emergency CAT scan which would probably take six weeks. Now I can spend a lot of energy trying to manipulate this, making calls, going here, going there. But I can't get you a CAT scan appointment as an outpatient. They're not going to give it to you. Nobody's going to give it to you no matter how you carry on.

The inequities and inadequacies of the New York City health care system have been made very obvious by HIV disease. They existed before HIV disease and will exist after, but even for nurses in voluntary and non-profit hospitals, there is a belief that the HIV infected patient is not a top priority. Medicaid patients everywhere do not get the latest treatment. And in the municipal system, as one nurse put it, "the administration would be happy if they [the HIV infected patients] would all just hurry up and die."

In a situation where assumptions and goals are contested, nurses have to be very clear about their own position. Chris T. told this story:

We had a doctor who cut himself while performing a minor operation on a 70+ patient. He nicked himself and he felt exposed. And he came in and he said to me, "I want you to test her [for HIV]." And I said, "You have to sign that form." And he said, "I want you to send her blood for testing." And I said, "You have to sign that form." The confidentiality law had just been passed which requires informed consent from the patient. He said, "I shouldn't have to get her permission. I just need to know. I shouldn't have to get her permission." I said, "I won't send her blood." He said, "You have to send her blood. I'm telling you to send her blood." I said, "I will not send her blood." I said, "You do not have a signed consent form. You do whatever you want, but I will not send the blood without a signed consent form." I said even if it wasn't illegal, which it was, it was unethical. So I would not do it. What I think he was trying to do was get me to do what

he wanted to do, so that he would have an accomplice, so that it would make what he wanted to do right in some way. I said, "Here are the forms, you fudge them, you're a doctor, you can lie about this stuff, you go ahead and do it and send it, but I won't do it for you. I'm telling you how to do it and break the law, you go ahead and do it."

Nurses have to be strong to do this work. They must be able to control their emotions. They must be able to withstand the opprobrium attached to caring for people with HIV disease. They have to deal with their own fears and ambivalences. They have to manage many patients who find it difficult to be compliant. They have to maintain a positive outlook despite the fact that treatments so far delay the inevitable. They have to manipulate the bureaucracy and, in many cases, challenge the power of doctors. They have to contend with a fragmented and crisis-ridden medical system. None of these conditions are exclusive to HIV infection, but HIV disease exacerbates them. As Emma B. described it:

I used to come home feeling that somebody had placed bricks on my shoulders, metaphorically and really, and not just the health issues but the philosophical issues. You get hit in the face with inadequate health care every day, you know that medicaid patients are not getting the same care as the people with private insurance, you just know it, and you know that a lot of your patients don't want to go to the hospital because they're going to end up on the wards where it's absolute hell. There's a fragmentation issue too, when somebody has medicaid, and they shuffle from clinic to clinic. If you have

three or four diseases, you get three or four clinics, none of whom are talking to each other, and they all lose your records anyway every time you're there. The paperwork during the Reagan administration tripled, because everything had to be justified, and also they are deliberately making you write more, to slow you down, also to discourage you from providing service to begin with.

Given the barriers to good care, nurses committed to HIV care have to have a clear understanding of what it is they are doing and why they are doing it. Fifty four percent (54%) of nurses interviewed and 55% of those surveyed cited overcoming bureaucratic obstacles as one of the real challenges they face. Forty four percent (44%) of those interviewed and 28% surveyed said they had to persevere through failure. Sixty eight percent (68%) of the interviewees and 57% in the survey said they had to work with colleagues who did not share their philosophy of care.

Some nurses defined what they did as simply what they were trained in nursing school to do. As Marcia B. said:

I was taught from day one, "You are the patient's advocate, you have to take care of all these needs." We spent a lot of time learning how to communicate with people, studying the social sciences, and a lot of other things which weren't strictly nursing. We were taught to look at emotional needs, social needs, just as important as physical needs.

This is the holistic nursing ideal, and it is indeed something which nurses have to embrace if they are to be effective nurses to HIV infected patients. But there must be something more. Nurses

have to demonstrate in their practice a belief in the merit and worth of the individual, no matter what that individual is like, no matter what he or she has done. To be an effective HIV nurse the practitioner must demonstrate tolerance and openness. As Roberta M. put it:

I don't want it to be an issue that I'm not gay, that I'm not black, and that I'm not Hispanic. I'm a health professional.

Being a health professional in these terms means focusing on the fact that the patient is a human being. It means disregarding social differences and distinctions. It means keeping in mind that patients are people, and as people, have certain rights. Nora J. put it very succinctly:

In the prison unit, I've taken care of people who were rapists, who were murderers, and my philosophy always has been that you leave your political convictions outside the door. You have to leave what you feel about certain classes of people outside the door. This is a patient. Especially with the prisoners, I used to say, this is a patient who is a prisoner who is a person.

And as Paula T. said about her IV drug users:

I like them. They're difficult but they're very good. Underneath all that other stuff that people make judgments about, they're really good people who just have had a bad break, or have had society's own judgment about the way people act or their sexual preference. I don't agree with that. I just feel that they're victims.

In this world in which there are not good and bad, but just people, every person has value. He or she may have almost no social

value, but they always retain moral value. It is this moral value which nurses honor and which they sustain through their practice. As they care for IV drug users and gay men, for women unlucky to have loved infected men, for men unlucky to have loved infected women, for hemophiliacs, for children who will not live long, they are making a statement. What they are saying is that human life is, no matter how short, no matter how abused, no matter how squalid, of great worth.

This is why the issues of DNR and pain control are so important to many of the nurses I interviewed. Talking about death and dying, presenting a piece of paper to a patient and watching them sign, helping them think about what is going to happen, all of these things are not easy. But if they are not done, if these issues are not explored, the patient may not die in dignity and may die in a manner they have not chosen but have been forced to accept. Dying in pain, stripped of the chance to choose, is not how human beings should die. For more than one nurse I interviewed, making sure that patients die well has become the reason for staying with HIV care.

This is why the images of nursing which these nurses retain are images of human connection. Gretchen S. said:

I kind of like thinking about it like walking with a patient arm in arm. That's sort of my picture. I might be a little stronger, but it's side by side. And maybe she leans on me, but there's something reciprocal there.

Many picture themselves sitting by or on the patient's bed, holding their hand, listening to them. Seventy percent (70%) of the nurses interviewed and 74% of those surveyed said that when they thought

of themselves as a nurse they pictured themselves listening to a patient, 68% and 69% respectively saw themselves talking with a patient, 60% and 55% were giving physical care, and 52% and 48% were sitting on or by the bed, holding the patient's hand.

The model most of us have of this kind of interaction is that of mothers and children, so it is no surprise that many nurses compared what they did to what mothers do. One male nurse said:

It's funny, really, I'm a man, but I picture nursing as someone with a white uniform, a woman bending over a bed, soft lights, the whole works.

Nina H. said:

Nurses are nurturing, think of the word 'nursing', the whole word meaning, where it comes from, which came first. I think the whole idea of nursing came from taking care of infants. It's like mothering. Not that you're not still doing dressings, and doing IVs and handling suctioning and nine million other nursing functions, but the feeling is you're sort of mothering them, showing concern, showing you care.

It is striking that the images most of these nurses, even those who are men, have of themselves as nurses are those frequently associated with maternal responsibilities and actions: listening, talking, giving physical care. Perhaps that is because maternal care is the best model we have, as a society, of disinterested concern for another human being. Maternal care is also sometimes the vehicle for a message about life itself. As Peter Berger says:

The role that a parent takes on represents not only the order of this or that society, but order as such, the under-

lying order of the universe that it makes sense to trust. It is this role that may be called the role of high priestess. It is a role that the mother in this scene [reassuring a child after a nightmare] plays willy-nilly, regardless of her own awareness or (more likely) lack of awareness of just what it is she is representing. "*Everything* is in order, [italics in the original], *everything* is all right" - this is the basic formula of maternal and paternal reassurance. Not just this particular anxiety, not just this particular pain, but everything is all right. The formula can, without in any way violating it, be translated into a statement of cosmic scope - "Have trust in being." (1990: 62)

If this is in some part the message of nursing, it is not surprising that it is transmitted in images of an attentive woman, and why, even for men, the practice of nursing can be visualized in female terms.

It has become something of a cliché in the literature on nursing and HIV disease to say that AIDS has brought about a return to valuing 'caring' (Fox 1990). Caring is seen as the emotional component of care, but many of the nurses I interviewed were careful to point out that good care does not necessitate emotional involvement. They made a distinction between caring for and caring about. Like Good's (1988) medical students, patient care is divided into technical and social realms. Martha C. said:

Any nurse is able to care for a patient, but I think to care about a patient allows you to invest a little bit more. It is not a prerequisite though, you don't have to love all the people you care for. But you do have to see if it's inter-

fering. Is it just that you don't spend much time with them, or is it that you're holding back pain medicine because they're obnoxious, or you don't clean them up because they're obnoxious, you make them wait? No, you don't do that, but if you don't take the extra time to sit down with them, it can affect the care. You have to think about it. You have to say to yourself, "Why am I not doing this? Is it better for the patient not to, or is it just that I don't want to go in and bother with him?"

Because nursing is a moral statement, its practitioners must be aware of their own actions, reactions and motivations. They have to be self-aware and self-correcting. Nursing is a self-reflexive activity. Sixty four percent (64%) of the nurses interviewed and 42% of those surveyed mentioned maintaining their own emotional balance as one of the challenges they face. Just as anthropologists continually question their reactions, so do nurses. They cannot simply follow their inclinations. Emma J. added this comment:

I just think that to be a good nurse you don't have to love these people. You have to really like people, you can't be just technically correct or you're missing something, and so is the patient. It makes such a difference if the patient feels you really care. You can do that without 'caring'. You make the patient think that you care what's going on in his life, and yet you don't really care about him as a person because you're going to meet patients you don't like. We have discussions about this [on the unit] all the time.

There are always some patients who forge real affective bonds

with nurses. Every nurse I interviewed had favorite patients they would never forget, but the fact that good care is given when the patients are not liked is the clearest proof that the nursing described by the participants in this study is a moral act.

It is done because it is the right thing to do. It is the right thing to do because this is how people should be treated. Thus for these nurses what they are doing is the expression of a social vision in which all people are equal. Beyond race, beyond class, beyond gender, beyond any kind of social criteria, the patient, as patient, is entitled to decent care. As Maria J. said:

I can't imagine being in these patients' position, but I feel that if I was, I would hope that there was someone who was treating me sensitively, would really sit down and talk to me, who I could feel comfortable enough with so I could open up to that person, and that that person would be sensitive and have a lot of knowledge about the disease, would know what I was feeling, the pain, the side effects of medication.

I would want someone like that to be available to me.

For the nurses I interviewed the goal is to be that kind of nurse, a nurse who can find a way to communicate with, care for, and comfort any kind of patient. For such a nurse, the connection with the patient becomes the avenue by which moral values and concepts are confirmed and celebrated.

In this sense nursing is not just about patient care; it is about something else as well. It is the elaboration of a moral order in which people as people, pure and simple, take the foremost place, and in which, as a result, the protection and care of people becomes

the most important goal.

Comparison of Interview and Survey Responses

Table 6

Question # 10: When you think of being a nurse, does a particular image come to mind, such as:

Response:	N	%
1. listening as a patient talks		
interview	3 5	70 %
survey	4 2	74 %
2. talking with a patient		
interview	3 4	68 %
survey	3 9	69 %
3. giving physical care		
interview	3 0	60 %
survey	3 1	55 %
4. sitting by a patient's bed, holding his/her hand		
interview	2 6	52 %
survey	2 7	48 %
5. walking arm and arm with the patient		
interview	2	4 %
survey	2 0	35 %
6. dispensing medications		
interview	1 0	20 %
survey	2 0	35 %
7. "being there" for patients		
interview	4	8 %
survey	1 1	19 %

XVI Death and Transcendence

It is doubtful, for two reasons, that a nurse without a moral vision which said people per se were the highest value, would choose HIV work. The first reason is that the disease is prevalent among groups on the margins of society. The homosexual communities in both New York and San Francisco were the first to manifest the disease. Although these communities were active and visible, they were also relatively isolated from mainstream society. Unless nurses had ties to those communities, they would not normally meet them in their work, except in small numbers.

IV drug users were even less likely to have much contact with healthcare personnel, except in drug treatment programs or in emergency care settings. The appearance of large numbers of gay patients and IV drug users in hospital settings was a shock to many nurses. Even if they worked in municipal hospitals, they had never seen so many before HIV disease brought thousands into the medical system.

When the disease appeared at first to be a disease peculiar to these groups, nurses who could see them as simply 'patients' were those who were most likely to step forward and take care of them. Nurses who saw them as unworthy of care for some reason, because of moral turpitude or social failure, found it difficult to care for them (Gee 1989).

The second reason why nurses need a moral vision which sees people, simply as people, as worthy of attention is that HIV infected patients require an enormous amount of work but have poor prospects. They need continual attention but their response to

treatment is always problematical. As Arthur R. described a recent patient:

I just had a patient who over the course of six weeks [had a succession of crises], first it was his Hickman [a permanent IV catheter] got infected, then he had new KS [Kaposi's sarcoma] lesions, then he became anemic, and one other thing, I can't remember what, got worse. And it looked as though it was all under control, but actually the Hickman infection probably never was under control, so he came into the hospital a couple of weeks ago, and went into shock and almost died. He was in ICU [Intensive Care] because everything was slightly crazy. They didn't know what was going on because the blood cultures were negative, but something had to be there, something that was killed by the antibiotic but not totally. He looked like he was going to die. He was on a respirator, they gave him medication to keep his blood pressure up, he was on three antibiotics, he was unresponsive for a period of time. He was bleeding, and he was pretty much unresponsive, and then, two days later, he got better.

This story could be repeated endlessly. The patient is very ill; everyone works very hard to keep him or her alive; they succeed; the patient lives a little longer, but will become ill again in the future, and the sequence of care and partial recovery will be repeated until death.

Although the nurses I interviewed were comfortable with the prospect that at some point active treatment should be discontinued, there is often now a long time before patients reach that point, and

nurses have to be ready to work hard to keep patients going while their ability to regain a high quality of life declines with each episode of illness. This effort is easiest to maintain when the patient's wishes are considered paramount and other considerations, such as social and monetary cost and efficiency, are ignored.

This is why all the nurses I interviewed said that decisions about treatment should be left to the patient. They believed that they could provide valuable information to the patient about the consequences of treatment and non-treatment. They also believed that other health professionals had a role to play in informing the patient, so that the decision would be based on sufficient information. But the decision had to be the patient's own. If the patient wanted everything done, that was acceptable. If the patient signed a DNR [Do Not Resuscitate] order and then wanted to take it back, that was acceptable. If the patient wanted only pain medication, that was also acceptable.

Only one nurse of all those I interviewed and those who answered the questionnaire raised the question of cost. For no other nurse was it an issue. The focus was on what patients needed and how it could be provided. At least with me, there was no discussion of how to allocate resources, or whether resources had to be allocated. The assumption was that since HIV infected patients are people, that was sufficient reason for the effort expended. As Maria J. said:

When nurses get to administration, they don't care about patients. It's just dollars and cents. I never want to be an administrator. I care about patients too much.

This focus on patients and the moral vision which excludes other considerations are necessary to HIV nursing but are not sufficient to explain why nurses remain in this kind of nursing and expect to stay with it. It is hard and difficult work with relatively few extrinsic rewards. As Cassie N. said:

Nursing is not pure nursing. There's a little bit of dietary, there's a little bit of being an electrical engineer, there's a little bit of being a doctor, being a janitor, being a handmaiden. It's definitely not what you see on TV.

Yet, despite the downside of nursing, and the nurses I interviewed did not try to gloss over the difficulties they faced, they liked taking care of HIV infected patients. One called it a "gift". It is a gift to both nurse and patient. The essence of the gift is the chance for nurse and patient to confront death and to construct, together, death's defeat.

Death is first literally kept at bay with treatment and care, but particularly with HIV disease, it is inevitable. As it comes closer, the nurse and the patient work to achieve a sense of the continuity of human life as well as an understanding of the individual's particular place in the endless cycle of human existence. In affirming the continuity of life, death, at this stage, is symbolically defeated, although the physical reality cannot be avoided.

The fact of death is a challenge to every human being's sense of self because death brings "biological and psychic annihilation" (Lifton 1979:18). The prospect of death, even for the healthy, often provokes terror and grief. Some people respond to the thought of death by denying both the expectation of death and its meaning. But most human cultures have responded differently, by searching instead for

immortality, and insisting that individual lives are somehow connected to eternity. Part of the horror and poignancy of HIV disease comes from its connection to sex, which is our most direct defense against fears of abandonment and nothingness, because procreation and reproduction are our most visible links to the future.

A belief in immortality serves as protection against the void and nothingness so overwhelming in physical death. It counters the fact of separation with faith in connection. Somehow some element of the individual lives on, in others' memory or in artifacts left behind. Perhaps the individual's life is incorporated into the divine. For some, intimations of eternity can be apprehended before physical death in transcendental experiences.

Thus the human search for immortality can take several forms. Lifton identifies five responses to death which all incorporate images of eternal time, "a sense of biohistorical continuity" (1979:18), an endless flow of life. These images are representations of eternity and they offer comfort and balm to human beings struggling with the fact of death. Nurses taking care of HIV patients use all five responses. They use them to counter their own and their patients' apprehensions by focusing on continuance and connection.

The first and most common approach to immortality is biological, "epitomized by family continuity, living on through - psychologically speaking, *in* [italics in the original] - one's sons and daughters and their sons and daughters, with imagery of an endless chain of biological attachment" (Lifton 1979:18). In the family the individual "finds his ancestors continuing mysteriously within himself, and in the same way he projects his own being into his

children and later descendents" (Berger 1990:62). Immortality is quite concrete because the same life which animated those who went before will animate those who come after.

This thinking can be easily extended beyond the family to the tribe, the organization, ethnic group, nation, or species. For caregivers themselves, it is often important that they feel that their efforts will benefit not only the patient but the patient's family and loved ones. Thus their beneficence carries forward into the lives of patients' children and onward into the future. In their service to others, practitioners experience this mode of immortality for their patients and themselves.

The second approach to immortality is religious. Through attachment to a particular creed, the believer is "offered the opportunity to be reborn into a timeless realm of ultimate, death-transcending truths" (Lifton 1979:20). This realm may be a personalized and material one, such as the City of God imagery of the New Testament, or it may be conceived of simply as a flow of divine energy, but essential to any religious vision of the hereafter is a belief in union with God or the divine life force.

By dying the individual becomes part of the eternal and divine. "For example, the Chinese peasant could die calmly in the assurance that he would live on in his descendents as his ancestors have lived on in him, but the Confucian gentleman could have the same assurance legitimated further by reference to the fundamental *tao* with which his life and his dying were properly attuned. (Berger 1990:63) In this schema, what happens on earth is incorporated into the divine order. For nurses who believe in life after death, part of

their practice, sometimes acknowledged, sometimes not, lies in preparing dying patients for the final step through which individual human lives become part of another, more permanent and more perfect, world.

The third approach finds immortality in human creativity. Creativity is commonly associated with works of art or science, but it is also a component of other human activities, particularly those which promise permanence. It constitutes monumental architecture's great appeal, some of the drive and energy which infuses business projects, even the creation of domestic life. Human action leaves its imprint on the world and on society; making a lasting imprint means that one's influence continues after death. For the nurses in this study, it may be that "making a difference" is one way of achieving immortality.

The fourth approach focuses on man's link to the natural world, "the perception that the natural environment around us, limitless in space and time, will remain" (Lifton 1979:22) after all our deaths. The recurrence of natural rhythms in nature, of death and rebirth, echoes our own pattern. In attuning ourselves to those rhythms, we participate in the limitlessness and eternity of Nature. Our embeddedness in nature becomes in this mode an avenue to immortality rather than a proof of our impermanence. Thus nurses' acceptance of the natural world links them to the permanence and infinity of Nature. When individuals are gone, the natural world remains.

The fifth approach to immortality is different in kind from the first four. It is to be found in experiences of transcendence which are

characterized by personal feelings of timelessness and infinity. The cosmic order is felt and it brings with it a vivid sense of life. Central to such experiences is detachment from immediate concerns and involvements. The self feels permeable, open to outside influences, yet focused and harmonious. As a result, there is "a temporary loss of differentiation of the self and the outer world ... (which) may lead to a lessening of alienation, to a rediscovery of the self, to a new set of values, to the finding of new potential for growth and development, and to a new beginning" (Lifton 1979:25). Both the patient and the nurse, if their encounters reach this level, experience pleasure and joy. They receive intimations of a kind of existence qualitatively different from normal human life, one suffused with ease and satisfaction, contrasting with the anticipation of separation and meaninglessness attached to the prospect of death

It is my contention that the nurses in this study use these various approaches as the situation demands in order to reconcile their patients and themselves to the central fact of human existence, the fact that we die. The holistic philosophy of nursing which they espouse enables them to use many different modes and to respond in different ways to their patients' needs for reassurance. If they saw their role as simply clinical, they would not be able to provide their patients with so many different ways of confronting and overcoming the prospect of death.

Some few nurses specifically spoke of their religious commitments and how these helped them in this work. The majority of those I interviewed, however, shied away from religious discussion or interpretation. They were reluctant to consider what

they did as religious in any sense, or even spiritual. But labels aside, it seems clear to me that what they were doing was providing a framework within which patients could feel that death was not the absolute end to their lives.

The nurse who arranged the photography exhibit for her patient was saying, "Your work lives after you." This was also the message of the video project: a record to leave behind which would outlive the individual. The memorial services and the quilts and the candles which many nurses used to keep the memory of their patients alive also said to patients that they would not be forgotten.

This is the paradox of HIV care. The individual patient and the nurse's relationship to that individual are at the center of care, but as the disease progresses the individuality of the patient, his or her personality, is very likely to disintegrate as the end approaches. The patient declines, physically and mentally, emotionally and psychologically, so that at the end the person with whom the nurse has forged a relationship is often gone. This leaves the nurse as witness to the patient as he was, not as he is at the moment of death. Many nurses in this study recognized that they were being asked to keep memory alive and that this was an important component of care. Memory is our strongest defence against the finality of death.

Many nurses I interviewed indeed tried to keep memory alive after death. They told me that they talked to the person as they wrapped the body up in the final ritual of care. They described patient's deaths to colleagues who were not present in the last moments. Many nurses tried to keep communal memory alive. As Cassie N. said:

When we first opened, we did a number of things which we don't do now. Originally we had the idea that we'd take pictures [of patients who had died] and keep a list of who had died when, but then we decided it would be too depressing for all the patients on the unit now. We used to hold memorial services once a month on the unit, just with staff who were on duty that day, a memorial to all the patients who had died that month on this unit and on other units. It had a religious overtone but it wasn't any particular religion. We'd read some poetry and we'd list the names, and usually the nurses would break into tears, and then it was over. We'd all go back to work.

As long as people are remembered, they are not really gone. One way to preserve memory is to listen to people's stories. Nurses are often asked to listen as patients review their lives. They also sometimes suggest that patients write their stories down, an enterprise which offers permanence and closure. Thus Stephanie C. encouraged one of her patients to start a journal. She said:

I have a woman upstairs who is doing a journal. She's the editor, she will decide what she wants in it, she's the narrator. She let me read the beginning of her journal, and it said, "Hello, old friend, I received you from a lady," and she goes on this way, talking to the journal as if it's a person, a friend whom she can tell anything to. She's a young black woman, thirty or so, and I guess she wanted me to know the pain but not directly, so she recounts [in her journal] an experience where she was raped. She writes like an angel, she could have

been a writer. She said, "I'm afraid of this thing called death, I'm afraid it's going to take me like the wind takes the dry leaves and put me out of sight."

By far the most common approach these nurses used was the biosocial one, the notion that we live on through our connections with other people. The nurses who arranged bedside reconciliations, who fought for custody plans for their patients, who made sure wills were signed, put dying individuals into the correct relationship to their families. These patients could feel that something of themselves continued in the world after they themselves were gone. The image of death was replaced with an image of life. The patient could feel "I live on in humankind" (Lifton 1979:20). In conveying this message, nurses say it to themselves as well.

These nurses enable their patients to die well, with a "measure of self-completion" (Lifton 1979:91), and a sense of integrity. They rescue their patients from disintegration in the face of physical death because their deaths are seen as "part of some immortalizing current of the vast human flow" (Lifton 1979:91). The individual's experience is connected to a collective "quest for a continuous symbolic relationship to what has gone before and what will continue after our finite individual lives" (Lifton 1979:17).

This message is conveyed to the patient by the nurse in all the myriad actions of care. These actions can be conceived of as rituals of connection, statements that in extremis the patient will not be abandoned. As Bob G. said of a patient he felt lucky to have visited when he did:

I remember one day I walked in on a patient, he had cancer,

a lymphoma of the lung which is fairly common with AIDS patients. He had pulled out his IV, he was lying with blood all over his bed. He was short of breath, the nebulizer to his oxygen was empty, so he was getting dry oxygen which dries out the mouth. He was just a mess. I put on a gown and gloves and I cleaned him up. I changed the sheets, I got him a blanket, I got him some ice water for his mouth. Then I filled the nebulizer and put it on him to make it a little more comfortable. He was dead that afternoon. I know that I had made him comfortable on the day he died, and I said to myself, "Thank God I didn't say, 'wait until your nurse comes along'." I just went and did it myself. I've had lots of moments like that.

What these nurses do is affirm the patient's life as he leaves it. Through their actions of care they tell their patients that their lives have meaning because their death is a part of larger rhythms of human life. The human condition becomes less frightening, less dreadful. Images of nothingness, of the void of death, are replaced with images of connection. The meaninglessness of death is replaced with the meaning of life, which lies in every human being's participation in the cosmic drama of existence. The individual's insignificance is transformed into significance.

In their practice, the nurses in this study perform actions of connectedness which dispel their own and their patient's fears of rootlessness. They place themselves and their patients in the great chain of being, linking the past to the future. They recover a sense of beginnings and endings and reestablish the 'mythical time' (Eliade

1954) within which human life is endlessly renewed.

For the nurse and for the patient, the actions of the nurse represent the link between the patient and all other human beings. The patient becomes the representative of all other individuals who must, at some time, face death. In ministering to the patient, the nurse embodies an image of human connectedness and human continuity. Caring for HIV infected patients becomes a life affirming act. It is this confirmation of continuity, that one's death is a part of life and life goes on, which gives the care of HIV infected individuals its vitality and its power.

The vitality also comes from the fact that it is a relationship with another human being, and that the meaning for the patient is also the meaning for the nurse. The nurse benefits too. As Gretchen S. said:

I'm really starting to think about this whole nursing process as an art as well as a science. And it's not something I would have considered before [HIV]. I would have said that if someone were a therapist, they were doing something that was more creative, more skilled, with their patients. I would have said that was not what I do with my patients. I really devalued nursing. But now, a lot because of the intensity of the relationship and the ongoing nature of it, and because there is so much at stake here, I feel there is something very creative, very special going on with people. I'm still working on this and trying to find out what's kind of moving it. But something happens, something happens there for me, I can't say for patients, but something happens there for me that is very

strong and intense, and real, and also very nourishing for me. I just really feel, and I'm not sure why, I'm just comfortable being there and talking to these people. There's some two way thing going on. I've just started to think of the value of silence, and just sitting with them, and letting people just know that you are there.

The experience of sitting with the patient, keeping them company in the most profound sense, is a visible activity symbolizing the connections among all human beings. This is what the nurse experiences as well as the patient. It is this understanding which the nurse quoted earlier referred to when she described waiting with the patient for death to arrive:

I remember the first one who died who I was close to. ... As I sat with him as he was dying, it reminded me of sitting with women in labor, giving birth. It's a very intimate experience. You don't know when it's going to happen, and you have to have the patient to wait for it. And it's momentous. It's happening and you have to give yourself to it.

Stephanie C. described it somewhat differently, but also emphasized the reciprocal nature of the relationship. She said:

I've found that the patients come to you in a situation where everything is going on all at once, the past as well as the present and the future, the family, everything, history, the whole situation, and you bring all of that too, of course, as a practitioner, and the meeting of these two in the middle, where you come together, I'm fascinated with this relational

self, of both myself and the people that I'm dealing with. In the middle there, there's a kind of alchemy takes place. And it's like no other patient relationship because every patient is unique. It's not always wonderful but it can be.

This is what these nurses look for in nursing and what they find in HIV care. For them, the pleasure of nursing lies in this reciprocal exchange. The rituals of care relate the nurse to the patient as much as they relate the patient to the nurse. Bob G. agreed:

It's almost like we're players on a stage, and here's a PCP pneumonia and a person, and I'm going to fulfill a role, I'm a nurse, and he's a person, and he's a person and I'm a person. We're going to work out this problem somehow, and we interchange and it's a holy thing. There's something that I can give and we can communicate between each other. It's just a wonderful thing that happens, and it's something that comes about in nursing practice, in that practice of nursing a patient, of enabling them to find what they have to do.

In these encounters the nurse's perspective dovetails with the patient's perspective. Together they create a common ground. Despite their differences, they "co-exist across the same world" (Spiegelberg 1976:556) and they become collaborators. Merleau-Ponty describes the experience of such interrelated subjectivities thus: "I am liberated from myself ... I lend him [the other] my thoughts and he makes me think in turn" (quoted in Spiegelberg 1976:556). The barriers come down, whatever the barriers might be which separate people, and a state of "pure focus, of inner unity and harmony"

(Lifton 1979:25) is achieved. It is in these moments that nurses and their patients transcend death as they experience timelessness together.

What these nurses work at creating in their practice is a space within which they and their patients can operate freely and simply as human beings. By ignoring the ephemeral criteria which distinguish one set of human beings from another, and by focusing on what connects every human being to another, they transcend a particular time and place. Their interactions acquire timelessness and they find themselves expressing eternal verities. In such experiences,

the restrictions of the senses - including the sense of mortality - no longer exist. Poetically and religiously this has been described as "losing oneself". It can occur not only in religious or secular mysticism but also in song, dance, battle, sexual love, childbirth, athletic effort, mechanical flight, or in contemplating works of artistic or intellectual creation. This state is characterized by extraordinary psychic unity and perceptual intensity. (Lifton 1976:43)

For nurses, experiences of transcendence occur when they perform those eternal gestures of human connection, those actions of physical care which contain within them the acknowledgment of a common humanity.

In such practice, the nurse acts in accordance with the moral precepts of the profession, and in so acting, feels in touch with the best part of his or her self. It makes nurses feel thoroughly alive. Rhonda P. described it this way:

People talk about nurses being wonderful saintly people, but that isn't what it is. You get so much from what you do. I'll give you an example. Not too long ago, I decided that I hadn't done enough patient care recently, and I needed a fix. We got a patient who was dying, and it was a complicated transfer. She came from another state, but they couldn't take her right away at the hospice here, so we were taking care of her for a while, and we couldn't find a nurse, so I said, "I'll go." Now she was actively dying, and she was staying with her brother and her sister. She was in an enormous amount of pain, but the two days that I spent with her were, and please understand the way I use this word, wonderful. I did so much for her. I kept her comfortable. I talked to her sister and her brother about her death, about what that would be like. I prepared them for it. I did all the things that made me feel good. I was exhausted when I left there, but I was on such a high, what I had been able to do, and the difference that I made. That's what it's all about. It's creativity. It's like nothing else. You're making something and you're making it better. There has never been anything else like it for me, never.

What these comments express is the power and pleasure nurses experience as they practice nursing. Conceptualizing nursing as simply taking care of people is only half of the story. Nursing is also about nurses, about how they know what they need to know, and what their way of knowing shows us about their way of being in the world.

XVII Contemplative Cognition

To be a nurse like those in this study, a practitioner has to be able to know the patient well, because nursing looks at how disease is manifest in the individual. The course which the nurse will devise for the care of a patient depends on the individual's reactions. Therefore nurses have to learn how to assess a patient clearly and intelligently.

The goal is not identity with the patient. It is understanding. This understanding is achieved through a particular kind of openness to the 'other' which in turn depends on a special form of cognition. This cognition utilizes sensory information, including both the patient's and the nurse's observations of bodily changes and processes, together with intellectual analysis and emotional responsiveness. Empirical observation, intellectual knowledge, and sensitivity to the psychological, emotional, cultural and social factors affecting the patient's situation are all necessary if the nurse is to understand and respond appropriately to the patient's needs.

Nurses use their knowledge of science and medicine to determine the patient's physical condition, but they must also use other knowledge, including feelings and intuition, to ascertain the patient's emotional and psychological situation (Agan 1987; Sarter 1987). In this process nurses must ignore their own prejudices and inclinations, without losing their own individuality.

Nursing process rests on this interaction, an interaction which depends on nurses' ability to be highly alert and responsive, both to the patient and to themselves. It is at the center of the meaning of 'care'. It is being attentive without being intrusive. It is being open

without being passive. It is being cooperative without relinquishing autonomy.

This depends, in turn, on a particular kind of mental operation which is based on the capacity to "harmonize passion and idea" (Lifton 1979:26) and to pass beyond the limits of one's own empirical knowledge. Only then can the patient be known as an individual with the same dimensions and integrity as one knows oneself. This kind of knowledge is key to the practice of the nurses in this study and it rests on their ability to link thinking with feeling.

This kind of mental operation can be thought of as the process of knowing concomitantly the subjective and objective status of the patient. It also takes note of the nurse's objective and subjective states. It thus combines two different viewpoints simultaneously. It is essential to the matching of perspectives which Merleau-Ponty describes in the encounter between two subjectivities (Spiegelberg 1976:556). The practitioner is open to both viewpoints at the same time.

The kind of nursing practiced by the nurses in this study depends on their ability to comprehend and incorporate the patient's perspective into a plan of care. This is achieved through a process I call contemplative cognition. In this process a myriad impressions register on the nurse's consciousness and have to be noted and sorted out all at once. There is no particular sequence to the impressions received by the nurse, but many different kinds of information are absorbed and integrated.. The physical condition of the patient, the patient's mental and emotional outlook, the patient's history, the patient's current situation, all of these aspects of the

patient's status have to be understood in themselves and then understood in relation to each other. At the same time the nurse considers these factors against what she already knows about the patient and the illness. During this process, the nurse is also aware of his or her own reactions and thoughts while directly focused on understanding the reactions and thoughts of the patient.

This process of understanding is similar to that often found in aesthetic, religious and empathic experiences. These contexts are not totally analogous to the nursing situation and it would be unwise to treat them as such. Yet there are aspects of what happens in nursing which comparison with aesthetic and religious experience can illuminate.

In aesthetic cognition, according to Watts and Williams, "one widely accepted tenet is that it involves a kind of distancing. We separate the object from ourselves" (1988:60). The observer puts the object outside the sphere of his own personal concerns and of his own needs and desires, and by so doing, is able to look at it on its own terms. This is an essential part of nursing. The patient is the focus of the nurse's attention.

In order to do this, intellectual restraint is required. The observer cannot be distracted by extraneous thoughts or introspection. He or she cannot indulge in mental commentary on related matters. Associations with other objects must be suppressed, otherwise the object won't be seen clearly, and clarity is the first prerequisite to cognition. In addition, the observer must stop thinking of the past or the future and be centered in the present. The observer must also "reach out" to the object rather than

remaining absorbed in his or her own reaction to it. Contact must be sought. Thus knowledge combines with desire (Furth 1987).

This "reaching out" must include some feelings of affection or reverence, otherwise all that is achieved is a purely intellectual critical analysis of the object, not understanding. Jerome Bruner, in his essay on viewing the statue of the Virgin Mary in Toledo Cathedral, describes the torrent of emotional impulses he felt. He wanted to "father her, be mothered by her, make love to her, gossip with her, and just watch how the face will change when the Child finally pokes her under the chin" (1969:70). Just so do the nurses in this study feel for their patients. Compassion pulls them towards their patients. They experience a "fellow feeling" for the sufferer (Gadow 1980).

But here too restraint is called for. The observer must not be carried away by his or her own feelings or the experience becomes an exploration of oneself, not an appreciation of the object. The observer must work at being receptive, without looking for any particular result. He or she has to let the event happen without directives, and must be careful not to become overly involved lest "in place of the experience of art, there is either a daydream or merely action" (Bruner 1962:72).

In religious cognition the same mental and emotional faculties are used and in the same way. The religious person learns to focus his or her attention on God rather than the self, and this attention is sustained and inspired by a love of God and a desire to know Him.

The result can be moments of illumination in which what is observed is discerned with directness and certainty. Such moments

are difficult to describe except by reference to poetic language. In Jamesian terms, they are often ineffable and noetic, meaning full of knowledge but difficult to convey to others. (James 1985) As E. Bullough has described them:

When a work of art is successfully apprehended in appreciation the new aesthetic object which is actualised to awareness is perceived with more lucidity, as if a veil has been removed from in front of it. It is sharper and more vivid in detail as if it had been removed from the periphery to the focus of vision and it acquires a structure by which it is compacted into a unified configuration. (quoted in Watts and Williams 1988:61)

This is similar to the understanding nurses achieve of their patients. When all the information has been processed, the patient becomes clear. The details coalesce into a pattern as the nurse comes to understand the perspective and history of the patient.

There is a particular kind of attention which facilitates this kind of knowing. For Simone Weil the key lies in being able to focus one's attention in such a way as to permit the free operation of the intelligence. One stops trying to force information into particular patterns and waits instead for the pattern to emerge spontaneously from the information. As she says:

Attention consists of suspending our thought, leaving it detached, empty and ready to be penetrated by the object; it means holding in our minds, within reach of this thought, but on a lower level and not in contact with it, the diverse knowledge we have acquired. Our thought should be in

relation to all particular and already formulated thoughts, as a man on a mountain who, as he looks forward, sees also below him, without actually looking at them, a great many forests and plains. Above all our thought should be empty, waiting, not seeking anything, but ready to receive in its naked truth the object that is to penetrate it. (1951: 111)

This openness is critical to the kind of nursing described in this study. It allows practitioners to know their patients and to know themselves. Because they are not self-absorbed, they can direct their focus to the patient. They are concerned about the other's well-being.

Thus their perception is open to feeling and they know what they know about the patient because they direct their feelings as well as their intellect towards the patient. As Suzanne Langer says, this is "perception molded by imagination that gives us the outward world we know" (1953: 372). Clifford Geertz describes it as:

a matter of giving specific, explicit, determinate form to the general, diffuse, ongoing flow of bodily sensation; of imposing upon the continual shifts in sentience to which we are inherently subject a recognizable, meaningful order, so that we may not only feel but know what we feel and act accordingly. (1973:80)

Empathic knowing of other people has always postulated vicarious emotional experience and the ability to see things from another person's point of view. It also seems to be non-analytical and intuitive. It is a way of being attuned to others while suspending judgment and it has sometimes been called "listening with the third ear" (Reik 1948).

Freud suggested that his students listen to their patients with an "evenly suspended attention" during which they were to avoid coming to conclusions or making judgments. The meaning of what the patients said would come clear in time and trying to force it into a preexisting frame of reference too early would cut off discovery (Watts and Williams 1988:64).

This way of approaching others is also part of the anthropologist's set of skills. The fieldworker must try to set aside any preconceptions and prejudices while making a sincere effort to absorb the others' point of view. Firm conclusions must not be reached too early. Rather what has been learned is allowed percolate through the fieldworker's consciousness until the significance of has been seen and heard becomes apparent.

As much as in anthropology and psychoanalysis, a kind of "evenly suspended attention" is essential to nursing. Nurses must be attentive but must resist being drawn too far into the patient's world. Yet they must be able to imagine what that world is like. The capacity to imagine, to imagine another's position and experience, to imagine another's reaction to one's own actions, to imagine the next need and anticipate it, these all facilitate the nursing process. Bob G., who said he spent much of his time listening to patients, went on to say:

It [nursing] is trying to throw away my preconceptions; it's sitting down and trying to define problems in a mutual way with the patient. It's asking them. I act as a reflector and what they say comes to me, and sometimes I try to order it so it helps them conceptualize in their mind what's going on. Some-

times I'll offer a suggestion or I'll try to offer choices. That's on an intellectual level. Sometimes it's just a hand on a shoulder. They need someone to touch them.

It is important, of course, not to confuse aesthetic, religious, and empathic knowing and to recognize that although the analogues are striking, nursing is not about works of art, or God, anthropology, or people's psyches. It is about caring for the sick and the well, and it is therefore, in this instance, towards the patient's body that the nurse directs a good deal of attention. Nursing is also practical. It is not simply about understanding; nurses use their knowledge to develop a course of action.

Still, the kind of cognition which occurs in nursing has many similarities to religious, aesthetic, and empathic knowing, and it plays a significant role in the kind of nursing described in this study. It is nonlinear, creative thinking which meshes reason and emotion (Furth 1987). Jacques Maquet calls this thinking 'contemplation.' He says: "The contemplative mode of consciousness cannot be reduced to cognition; neither can it be reduced to affectivity" (1986:166). It is both together.

In this kind of mental activity the nurse uses her reason and feelings to understand the patient and the disease. It is what is happening when the nurse studies the patient, putting together what she knows about the patient and the disease. It is the nurse's skill at combining clinical knowledge with emotional sympathy which enables her to decide to act in a way which relieves the patient's discomfort, whether that discomfort is physical, social or psychological. The nurse is the medium who processes many

different kinds of information and who, from that conglomeration of information, makes a coherent pattern or picture of what is happening to a particular patient. When the picture is complete, when enough information has been gathered, the patient is seen with clarity and decisions about how to care can be made. Yet the nurse's own ego is not involved. The other person has priority. In Maquet's words, "The beholder's ego is not the conquering ego of action, the assertive ego of [pure] cognition, the introspective ego of affectivity. It is the disappearing ego of contemplation" (1986:165). In reaching out to the patient, the nurse can attain "a true and authentic transcendence of [the] self" (Gadow 1980:91)

Nursing understanding, like anthropological understanding, is based on experience, the experience of meeting the unfamiliar and making it familiar. To do this the unfamiliar must first be construed as worth investigating. The outcome must be seen as valuable. Then the nurse, like the anthropologist, must approach the investigation with a minimum of preconceptions and prejudices and the maximum of sympathy and interest. The nurse's individuality is subordinated to the patient's. The focus is on the 'other'. It is the patient's story which is important. The patient's views, like the native's, must be solicited and integrated with information from other sources. Finally, the assessment of the patient, like the writing of an ethnography, depends in some measure on the personal attributes, background, interests, and ambitions of the nurse.

In nursing and in anthropology, knowledge of the other is the gateway to understanding. This is a kind of knowledge which is personal and infused with feeling. It is different from scientific

knowledge. As Merleau-Ponty points out:

Science manipulates things and gives up living in them. It makes its own limited models of things; it operates upon these indices or variables to effect whatever transformations are permitted by their definitions. It comes face to face with the real world only at rare intervals. (1969:252)

Science is concerned with making general laws which facilitate prediction and its object is "to reduce empiricism". (Bruner 1962:74) This is exactly what this kind of nursing is not about. Nursing uses general knowledge; it needs science, it contributes to scientific knowledge, but it is not science in Merleau-Ponty's definition. This kind of nursing, like anthropology, does not try to escape from the empirical situation. On the contrary, within the empirical situation the nurse finds the knowledge needed to care for the patient. Each nurse has her or his own knowledge of each patient. This knowledge is individual to the nurse. Yet it is knowledge which is used to construct a course of action, and it thus passes from the subjective to the objective.

In this process there are always elements which remain ineffable, which cannot be communicated. Many particulars of how the conclusion was arrived at can be enumerated but they do not, in themselves, add up to understanding. Michael Polanyi describes this as the unspecifiability of personal knowledge. We know that we know and we know what we know but we cannot explain completely, or to another's satisfaction, how we arrived at our knowledge. As Polanyi says: "Although the expert diagnostician, taxonomist and cotton-classer can indicate their clues and formulate their maxims,

they know many more things than they can tell, knowing them only in practice, as instrumental particulars, and not explicitly, as objects" (1962:88).

Not everyone has the talent or capacity for the kind of thinking which blends subjective and objective observation and which entails simultaneous awareness of one's self and others. It is a skill which requires practice. Anthropologists learn it in fieldwork; nurses in their practice. But just as anthropologists do other things than fieldwork, so nurses are not always engaged in intimate encounters with their patients.

This kind of contemplative cognition is not needed in every nursing setting. But it is essential to nursing HIV infected patients and I believe that the nurses who are attracted to the care of HIV infected patients do it well and enjoy doing it. It is what they are doing when they struggle to figure out the appropriate intervention for a particular patient. It is what they are doing when they practice holistic nursing. The opportunity to engage in this kind of knowing is one of the attractions of this disease for these nurses, and the length of time HIV infected patients spend under their care gives them opportunities to use and improve their skills.

Nurses who care for HIV infected patients need to be adept at this kind of personal knowing for two reasons. The first is that HIV disease is a new disease and its natural progression is not yet definitively known. Indeed, it seems to manifest itself differently in different groups and in different countries (Harawi and O'Hara 1989). Nurses often therefore have to rely on their own judgment with HIV disease, more so than with diseases more fully understood. They

have no script to rely on. The second reason is that, because HIV disease afflicts a disproportionate number of marginal people, a nurse has to be able to get beyond the attributes of marginality and see HIV infected patients as people.

A nurse committed to HIV care must be good at observation, must enjoy the intellectual puzzle of coping with something unknown, must be self-aware yet self-forgetful, and must feel for her patients. Such a nurse is close but distant, engaged but disengaged, sympathetic but restrained. These are contradictory demands, and satisfying them is the hardest thing nurses do. It means being true to oneself and to others at the same time.

Achieving this state of balance is difficult and difficult to sustain over time. Anthropologists also not infrequently find their ability to engage others in this way decreases as time goes on. Because this process must be repeated with each patient, nurses get tired and lose their energy. It may also be a capacity which ebbs and flows, so that nurses and anthropologists may be more or less capable of it at different periods of their personal and professional lives. This, I believe, is one reason that nurses change positions so frequently. One nurse told me she moved every eighteen months. Moving provides nurses with respite. Many move back and forth between positions which involve intense patient contact and those which are more impersonal. Such a pattern was clearly visible in many of the work histories of the nurses in my study. One nurse moved from an inpatient AIDS unit to an ambulatory clinic to a day program to an administrative position in a hospital, and then at the time of our second interview, was about to return to clinic work.

Another nurse worked for five years with HIV infected patients in homecare, and then took a position in epidemiology. At the time of our second interview, she said she was ready to go back to direct care of HIV infected patients.

Another difficulty with this kind of practice is that it can only go as far as 'others' permit it, so it is a limited knowledge. It can't be hurried; the 'other' sets the pace because it is collaborative. And because patients do not always understand their role in the process, nurses can become frustrated. In addition, because the organization and ethos of the American system gives little more than lip service to this part of nursing's enterprise, nurses burn out.

This way of understanding and relating to patients is only taught obliquely in nurses' training. Like their counterparts, fledgling anthropologists, young nurses watch other nurses and incorporate what they like from what they see. This is both good and bad. As Cassie N. said:

I think it [HIV care] attracts people who can do this. I don't think they're trained. I don't think that nurses in any school are given bedside manner classes on how to relate to patients, how to be emotional. You're always told the same thing: treat them with respect, blah, blah blah, You develop it on your own in clinical [practice]. Nobody tells ____ to dance for her patients or tells us to sing for them, to make friends with them. It's not something you have to do. It's just something you do.

Because the relationship with their patients which these nurses describe is not taught specifically, it is liable to misunderstanding.

Young nurses can become disillusioned when they first start working because they do not experience the kind of personal relationship they expect with their patients, particularly in hospital work. Yet their picture of the desirable personal relationship may be an immature or incomplete one. It may focus too much on expending and accepting emotion, whereas in the experienced nurse, feeling is used to expand knowledge about the patient. It is emotion in discipline to the intellect. It is sympathy, not sentimentality.

The nurses in this study were, with a few exceptions, mature women and men with years of nursing experience. They understood how to control their emotions and how to use their emotions to achieve their desired end. That end was knowledge, not emotion. Their goal was to understand the patient.

This is why nurses can say that "love", in the popular sense, is not what they do, but it may be what Merleau-Ponty meant when he speaks of "adult love" as taking "the other person as he is, at his distance and in his autonomy" (1969:95). It is what Weil is describing when she says:

The capacity to give one's attention to a sufferer is a very rare and difficult thing. Warmth of heart, impulsiveness, pity are not enough. ... The love of our neighbor in all its fullness simply means being able to say to him: "What are you going through?" It is a recognition that the sufferer exists, not only as a unit in a collection, or a specimen from the social category labeled "unfortunate", but as a man, exactly like us, who was one day stamped with a special mark of affliction. (1951: 114)

The nurses I interviewed are nurses who find in the care of HIV infected patients an opportunity to use all their nursing skills. Those skills are intellectual, emotional and physical. It is through using them together, rather than singly or sequentially, that nurses come to understand their patients and how to care for them.

Instead of privileging rational activity, which is what modern consciousness does, this kind of nursing gives equal weight to the information gained from physical contact and from emotions. Like the practice of anthropology, it meshes the ability to be objective and analytical with the exercise of empathy and intuition. Yet it also insists on "hands on", direct contact with the patient. This kind of nursing thus offers to its practitioners a way of being in the world which keeps the body, the mind, and the heart together. It demands of practitioners "a participation of the entire self, ... a unifying and directing of one's entire self in relation to another's need" (Gadow 1980:90). It is achievable only by nurses "who act out of an explicit self-unity, allowing no dimension of themselves to be exempt from the professional relation" (Gadow 1980:90).

XVIII The Appeal of HIV Care

The encompassing conception of nursing which the nurses in this study profess is difficult to honor in the workplace, but HIV care does offer many of them an opportunity to put their ideals into practice. As Bob G. said:

When I was in nursing school, I was told wonderful things by my professors, wonderful things about what a nurse can do. There was a wonderful sense of scope in what a person in the practice of nursing could do. And then to get out into the reality was something else. I worked in ER for six years, and saw the inhumanity that was going on, and I had very little contact with people who thought the way I did. I often got discouraged but I think in this work in the last year, with the talents I've got, I've found that what I thought in nursing school was possible is possible. My practice is validating my beliefs or my belief in myself or my belief in the talents I have. It's that validation that is so rewarding.

The "wonderful things nurses can do" are not limited to HIV disease, but there are a number of reasons why nurses who want to practice with this ample reach are attracted to HIV care. Nurses can find in HIV disease itself an opportunity to develop the kind of care they want to provide; HIV infected patients need many different kinds of services and special attention. This is the subjective aspect of HIV care; it satisfies the desires of some nurses to practice in a particular way.

In addition, because HIV care lacks status within the medical system, it attracts less institutional attention than other diseases.

Physicians and hospitals do not compete to be known as the foremost HIV center. As a result, nurses dedicated to HIV care are given more autonomy and independence to develop their own practice than nurses in other specialties. This is the objective aspect of HIV care.

The autonomy nurses find in HIV care takes several forms. First, nurses in HIV care tend to be left alone more than in other specialties. They are freer to create their own practice. As Bob went on to say:

I guess it's because we make our own job. The way it evolved in the hospital, we're not even under nursing. They don't control us. They don't have us doing QAs [Quality Assurance]; we don't have to go to the meetings on all those things. My boss is the nurse who started the program and then the doctors, and the doctors don't know much about nursing. They just leave it to us, "OK, nurse, do your thing". They know it's valuable and they appreciate that. Whatever we can come up with, it's good in their view.

This attitude gives nurses the chance to experiment and innovate. A nurse who was going to be in charge of an ambulatory clinic for HIV infected patients commented:

It's not like blood pressure clinics where everything is set. The ideas about how to run a clinic have been developing for years and we still have a lot to learn about the mechanics of it; we don't have a number machine for example; still on things like patient education, we're way out in front.

Patient education is essential if the transmission of HIV disease is to be contained and/or halted, and through patient education

nurses can have an impact far beyond the individual case. But influencing people and promoting behavior changes are much more complicated than following correct protocols and established routines, important as they are. Developing approaches and programs that work calls for ingenuity, inventiveness, and variety. The nurse quoted above detailed the various steps she would institute when she was in charge:

Right now the clinic doesn't offer condoms. It's just the way the clinic has evolved. I would put out condoms, I would try to find folders and handouts for people, trying to anticipate problems, about diarrhea, about nausea. I would have a little present for them every week. I'd do the kinds of things which aren't being done now, which reflect what I have to offer.

The concept of what the nurse has to offer can be broad in HIV care, and it is up to the nurse how much is offered. It's not just the clinical skills, it's other capacities as well. And foremost among those capacities is the capacity to feel. Agnes S. said with some wonder:

We had a patient who was very, very anxious, and you always had the feeling that you could never please him. It didn't matter what you tried to do. He was real anxious and he became very angry and disagreeable, he wasn't making any friends at this point. But his lover was there to smooth ruffled feathers, and I got close to him and how he was feeling, and he was there when he died. I saw him crying and I just felt like I had to cry and I had never been that way before. I had always been real strong and tough, and this softens you up.

Nurses' training can promote unfeelingness if it denies the impact of feeling. Toby B. commented:

When I was in school you were always told to be 'professional' which means showing no emotion, neither anger nor sadness. If you were upset and tearful, you had to remove yourself from the situation; you had to go to the bathroom and cry. God forbid that you should ever show a patient you're compassionate or that you feel for them, you care for them, that this is affecting you.

The nurses I interviewed thought it was neither desirable nor possible to be such an automaton. Toby counseled the young student nurses under her tutelage to acknowledge their feelings, both positive and negative, for the patient:

If you have feelings and emotions, then show them. This floor more than any, you have the opportunity to do that. If you are sad, there's no reason why you shouldn't cry with the patient. I do it. I go in there and cry. Sometimes you're angry. Some patients just get you downright angry. They'll be rude and I'll say to them, "I didn't deserve that. I'm trying to help and you're pushing me away. You're yelling and being obnoxious." I had one patient who was very difficult, so I said to him, "Nobody wants to take care of you. I've got 55 nurses on my staff and nobody wants to take care of you. I can see one person maybe having a personality problem but not 55." He got better behaved, but I had to be very straight with him.

HIV nursing gives these nurses the freedom to be fully and

humanly involved in their work. Just as these nurses take a holistic view of the care their patients need, so they want to be able to bring all their faculties and talents to bear on the task of caring for HIV infected patients. They become holistically involved themselves in their patients' care. They are not simply the technicians and the experts.

They remember funny stories to tell their patients. They talk about movies they've seen or trips they've taken. They keep track of birthdays. They bring food and flowers to their patients. They sometimes get involved far beyond what other nurses might feel are the boundaries of care.

Gretchen S., for example, spent a great deal of time helping aone of her patients arrange for custody of her children. She consulted a friend who was a lawyer because her patient wanted to separate her children, giving one to her mother, one to her sister, one to an aunt. The lawyer's opinion was that the judge would throw this arrangement out because it separated the children. The nurse then went back to her patient and helped her devise another plan. Later, after the patient died, she found herself involved in complex negotiations with a funeral home and the New York City Welfare Department. The funeral home wouldn't pick up the body from the hospital until it received some money; the patient's family had no money; welfare had to go through channels before releasing the money. Meanwhile the patient's body lay unclaimed.

The objective situation of many of HIV infected patients matches the subjective desire of these nurses to go beyond clinical requirements. Because so many HIV infected patients lack family

support, hospitals take on responsibilities once reserved for patient's families, and so nursing them can mean being involved in issues which used to be handled by family members. HIV disease has revealed how isolated and alone many people in American society are. Part of the goal of the nurses in this study is to demonstrate to HIV infected patients that they are not alone.

In order to do this, the nurses in this study often go outside the strict limits of their 'professional' role. Nurses who are willing to go this far for their patients frequently favor an open kind of practice. They respond in many different ways to their patients and they recognize that their patients have a number of different responses to their disease. So, for example, they are frequently open to what non-traditional treatments may offer their patients. As Cassie N. said:

You certainly learn a lot up here. You learn about alternative medicine. I have patients who believe in crystals. I have patients who believe in special machines and Chinese herbs. The way I feel about it is, as long as you don't give up on conventional medicine, whatever you want to add to it that's not harmful, that's fine. If you want to sleep with crystals on your chest, if you want someone to come in and spray incense in your room, that's all fine with me as long as you don't give up on conventional medicine. I've had people on macrobiotic diets, all of which are accepted by a great part of the community here. I've never found any of these things to work, but if they make you feel better and if they put your mindset in the direction of getting well, it's not going to hurt.

The nurses I interviewed were open to other perspectives because they could not cure, but sought to heal their patients. Patients would never be HIV free, but they could be restored to psychological wholeness, to a renewed sense of self, to revitalized living even though ill. Whatever promotes this process is therefore good, whether it is strictly medical or not. It might mean incorporating mental imaging into their program or experimenting with electrical stimulation to alleviate peripheral pain. Thus part of the freedom HIV care offers to these nurses is the freedom to bring other than medically approved therapies into the system. Because administrators and doctors give HIV units more latitude than other units, sometimes for compassionate reasons, nurses can experiment. They can respond with more than the traditional array of medications. And they can, if they like, respond with more of their personal selves than they could in another specialty in which protocols and therapies were more defined.

Responding personally means that the nurse is not afraid to reveal personal information to the patient. Some of the lines which are usually drawn between patient and caregiver are erased. Bette V. used her artistic ability to create fantasy objects for her patients, saying "I like to do things with my hands, I draw and paint, it's a gift and a comfort, I think, for the patient."

This is holistic work because the practitioner calls on a personal repertoire of knowledge as well as professional training. It requires courage, the courage to be open and to risk exposure. It means being ready to risk humiliation. Like the fieldworker in a strange culture, the nurse may jeopardize the nursing enterprise by saying the wrong

thing, making the wrong gesture, antagonizing or offending the patient. It can be a daunting prospect, and even those who feel a strong desire to work with HIV infected patients because it will let them practice this way, feel some trepidation as they begin. Maria J. said:

I always felt that these particular patients' [HIV] needs weren't being met. The fear of providers was enormous. Patients would die and no one would know what to do with the family. That's how I got into this. But when I got this job I wondered emotionally if I was going to be able to do it. If I couldn't do it emotionally, what good was I going to be to the patient? I thought about it for a week and I said, "I don't know if I can, but I want to do this so badly. I care so much. I'll give it a try and see how patients respond.

In this statement we can see the ambivalence most fieldworkers in anthropology also at some time experience. The challenges seem too great, the rewards too meager. It is tempting to consider giving up. Nurses, like anthropologists, tack back and forth between exhilaration and discouragement. Some days are terrific, when progress seems assured. Some days are terrible, when progress stalls or decline begins. HIV disease is not only a roller coaster for the patient; it is for the nurse also.

Yet they do stay with it, despite the difficulties. The reason they do is that HIV care offers the nurses I interviewed the chance to be themselves in their work. The work may be difficult, but the nurse wants to be there. As Maria J. went on to say:

It's depressing, it is. The patients come and go and eventually

they die. That's the hard part. But I feel a lot happier, a lot more satisfied now than I did when I was a general surgery nurse. I get to do a lot of teaching and spend a lot of time with the patients. You have to be so sensitive. You are required to spend more time with the patient. They feel better. I feel good about that.

Toby B. was even more emphatic: "This is the happiest and the most fulfilled I've ever felt in nursing, including the ICU, the ER and anything else." It is satisfying because what the nurse has to offer and wants to offer is exactly what is needed. Paula T. added: "I'm where I'm needed, and I'm getting tremendous personal satisfaction from the knowledge that I'm competent and that I'm caring and that I have something to offer."

Nurses have always been competent and caring, but they have often been relegated to the shadows. They frequently worked in the background, taken for granted. What a medical crisis does is make visible how important nurses are. This was true in the Civil War, in the epidemics of the 20th century, and in the military conflicts of recent memory. It is also true of HIV disease.

What is also true of HIV disease is that the healthcare system has not been able to cope with the challenge of the crisis. There are not enough physical facilities, there is not enough medical knowledge, there are not enough people to do what has to be done. The procedures and protocols are not established. As a result, medical institutions have to relax their control, and, as a result, some of the antagonism between nursing and the institutional framework within which it operates subsides.

Nursing, like other predominantly female professions, draws its values from the private sphere, but the institutions within which nurses work are organized on public, bureaucratic, and universalistic principles. Nursing looks at the individual, focuses on need, and adjusts to circumstance. It is somewhat ad hoc. Hospitals and clinics and agencies are not.

They are, like all bureaucratic organizations, concerned with order and predictability. Standards are established which are to be applied across the board, and these standards are to be applied impersonally and with "affective neutrality" (Berger & Berger 1974:52) Both caregiver and patient are assumed to be somewhat featureless and anonymous. The focus is on following the proper procedures, the means which will result in the desired end. The consciousness within the bureaucratic organization is one of abstract depersonalization. Emotion is controlled and directed. As Berger and Berger comment:

Bureaucracy assigns emotional states. The bracketing of personal bias, the objective assignment of cases into their appropriate boxes, the painstaking adherence to proper procedure even in situations of great stress - all of these are not just elements of cognitive style but presuppose specific emotional controls. (1974:58)

For nurses whose values are different from those dominant in large organizations, the experience of working in bureaucratic organizations can be painful. So much of what they believe and what they seek to do is directly contrary to the fundamental principles underlying the institutions they work in. As Berger and Berger note:

At least potentially, this constitutes a threat to the individual's self-esteem and, in the extreme case, to his subjective identity. ... One may safely generalize here that the threat will be felt in direct proportion to the development of individualistic and personalistic values in the consciousness of the individual. Where such values are highly developed, it is likely that the intrinsic abstraction of bureaucracy will be felt as an acute irritation at best or an intolerable oppression at worst. ... The individual whose allegiance is given to such values is almost certainly going to resent being treated "as a number". (1974:56)

There is thus a fundamental contradiction between nursing and the institutions which hire nurses. It is this contradiction which working with HIV infected patients reconciles. In HIV care, the institutional values take second place. Particularly in dedicated units, clinics and agencies specializing in HIV infected patients, institutional power is relaxed. Nurses can sometimes determine how their units run. Staffing and hours can be adjusted to the needs of the patients and the nurses. Nurses find that they acquire autonomy. As Cassie N. said:

We're understaffed, but a lot of us do overtime, so that we can keep the unit staffed with people that we know, and of course there are monetary benefits for those of us who do it all the time. There's no question about that, but when we first opened, we were relying on the hospital to give us nurses from a per diem pool, and they just couldn't meet our needs. So now we're trying to book our own, that is we sign up for overtime

knowing that we'll be on this unit, and it seems to be working better.

In many instances, nurses can follow their own bent and institute a kind of nursing within their units and clinics, and with their home care patients, which is congruent with their principles and ideals.

Thus it is not only the match between nurses' individual subjective inclinations and the objective requirements of the patients' needs which makes HIV work attractive to the nurses I interviewed. In HIV work there is also more of a match between the institutional organization of care and nurses' principles. Thus some of the strain nurses commonly feel in their jobs is removed and nurses can concentrate on what they like to do and what they're good at doing.

At the same time, in doing what they like to do, nurses in HIV care now find that their perspective is espoused by some in the medical and political establishments. Until very recently, medicine treated all patients alike, with similar drugs and similar dosages for men and women, for blacks, hispanics, whites and Asians. Now there is a growing recognition that because women have not been included in much medical research, the conclusions cannot be automatically extended to them. There is a further recognition that different ethnic groups have different vulnerabilities and respond differently to drugs. Medicine is becoming somewhat more nuanced, more subtle in its applications.

In this respect it is coming closer to nursing, which has always said that the patient, as an individual, must be considered as well as the disease. In HIV care this convergence is not only more apparent

but more necessary, since the disease expresses itself slightly differently in each patient. Thus for the nurses involved in HIV care another source of tension and conflict is diminished. Nursing's viewpoint is validated. Individual doctors are still difficult, policies are still restrictive, but in some important ways, in HIV care, medicine itself is less monolithic than it once was and more receptive to nursing. As Chris T. commented:

One of the things I think AIDS has done within the medical system is loosen the boundaries between the professions and between the role descriptions. It provides an opportunity for people to grow professionally.

In addition, this kind of nursing's emphasis on the patient and its focus on the idiosyncratic expression of disease aligns it squarely with the dominant values of American society. Concepts of individual choice and notions of self-direction are central to HIV care. The nurses I interviewed were unanimous in placing the right for final decisions about treatment with the patient. This is consonant with the stress American society places on autonomy and independence. Patients are to be given the right to choose. They are to agree to treatment. Decisions are not to be made for them. This is an anti-authoritarian and egalitarian viewpoint.

The nursing carried out by the nurses in this study finds an echo in the major political movements of the past thirty years, the civil rights drive, the gay liberation and the women's movements, because it emphasizes the right of the individual patient to choose. In New York City, these are powerful forces. For nurses in HIV care this means that they can work without feeling that they are all on their

own. In Peter Berger's terms, they are not in the position of a "cognitive minority, a group of people whose view of the world differs significantly from the one generally taken for granted in their society" (1974:6). They may have to defend their point of view but they have the comfort of knowing that, no matter what the individuals they have to struggle with believe, there are many other people in the New York area who see issues as they do.

A crisis frequently calls into question ordinary ways of doing things. What has been taken for granted is often examined anew. With HIV nursing, this examination has reaffirmed the validity and value of nursing's traditions, most particularly its concentration on the individual. Nursing has always functioned this way but only recently has the congruence between nursing's values and overarching communal values become so apparent. Nursing's point of view is compatible with general American values of autonomy and independence, and in New York City, nurses committed to HIV care have the support of prevalent political and social attitudes.

Thus in responding to HIV disease, the nurses I interviewed are being true to themselves, to their profession, and to their social beliefs. They can respond to the disease according to their own scale of values because the institutions they work in have relaxed some of their control. Thus, HIV nursing is a specialty in which there is less tension than in most occupations between what produces success professionally and success personally. Strategies which support honesty, sincerity and authenticity, which are personal virtues, are not at variance with the strategies necessary for professional competence. For these nurses, in this work, their personal self is in

harmony with their professional self, their political self and their social self. It is this congruence among so many different fields which makes HIV care so attractive and so satisfying to the nurses I interviewed. For these nurses, HIV care is indeed a special world.

XIX Images of Care

The images of themselves which the nurses in this study hold are images of physical care and connection. Patients are in bed, nurses are sitting by them, holding their hands, listening as they speak, responding in turn. Sometimes nurses and patients move side by side, linked arm in arm. In every setting, nurse and patient touch. This is emblematic of the contact which must occur in other domains as well if the nurse and patient are to work together.

Even for nurses who are male the image of the nurse is an image of a woman. Certainly the behavior represented in the image is that associated with women, since it is women in American society who are responsible for the physical care of children and family members who are ill. Perhaps that is why the male nurse quoted earlier said of his own image of a nurse:

It's funny, really, I'm a man, but I picture nursing as someone with a white uniform, a woman bending over a bed, soft lights, the whole works.

Images of nurses held by the general public in American culture are usually female figures. Indeed, the preponderance of women in the profession and its genesis within household responsibilities have tempted some to suggest that femaleness and nursing are archetypically linked. Woman equals Nurse and Nurse equals Woman are familiar equivalences in the popular mind (Fiedler 1988). This easily moves on to the equivalence of Woman equals Mother and so Nurse equals Mother.

It may be, however, that the image of the nurse as a female has less to do with biology and more to do with the fact that it is

within relationships with women that members of the American culture experience that personal attention which is at the center of care. It is also generally within the domain of domestic life in America, a domain under female control, that this kind of relationship is learned and practiced. Therefore to represent this kind of a relationship, a female figure is used because it brings with it the ideas of care and attention. Nurses are not mothers, but they sometimes act like mothers and their patients sometimes act like children. It is this analogue which the image seeks to project, bringing diverse domains together through the representation of a female. There are male nurses too, but the male figure in American culture does not elicit the same response. Therefore a male figure bending over the patient does not come automatically to mind when nursing is pictured.

Personal care in American culture is the province of women, and so images of nurses as women reflect social reality. Women are the caregivers in American society, and they are socialized more than men are in the skills of empathic understanding. They are taught, more directly, more concretely, and more completely than men, to "think of others". As a group, therefore, they are more apt to come to nursing with some of the skills needed in a profession based on personal relationships. Whether socialization builds on a natural propensity is open to question, since the answer to such a question depends on men being raised as women. Still women are more likely than men to be able to use imagination and emotion as a pathway to knowledge because their social role in American society has been largely defined in affective terms (Belenky 1986; Jagger 1989; Keller

1985; Tronto 1989).

In addition, because their role has traditionally been defined in affective terms, women in America may be more likely than men to seek in their work the kind of convergence of emotion and thought which the nurses I interviewed have found in HIV care. Thus women's demands on work may be different from men's, whose socialization encourages them to separate their lives into distinct domains with distinct repertoires of thought, feeling and behavior for each. The expectations women bring to work, expectations about the meshing of domains, are very much at variance with the structure of work in American society. Women's socialization encourages integration; work in a technological and industrial society discourages it.

This is part of the reason why the crisis of HIV disease is an opportunity for the nurses I interviewed. It is an opportunity for these nurses to bring together in their work their intellectual, moral, affective and social worlds. In the doing that is this kind of nursing, all these domains become one. The meshing of domains, for the patient and the nurse, is what holistic nursing is all about.

Being involved in HIV care is also a way of being fully a part of the historical moment. HIV infection is a particular disease at a particular moment of time. The nurses in this study each have a particular history which they bring to their work in HIV care. Nursing has a history too. The treatment of illness, and the treatment of the poor, minorities, homosexuals, women etc., have histories in America. These elements come together in HIV care, so that the playing out of the drama of HIV disease is in part a playing

out of social as well as individual narratives.

It is this complexity which provides the richness in HIV work. For the nurses in this study their work is an opportunity to live fully, and to live out some of the major social issues of our time. They see what they are doing reflected in the media, in professional journals, and in political debates. They are part of one of the central dramas of our century.

In addition, they find that all their knowledge and all their skills, personal and professional, are needed to care for HIV infected patients. This is not what most workers find in their jobs. It is certainly not something that the institutions which hire nurses are concerned about. Nor something that the medical system as a whole strives to make possible for any caregiver.

What has made it possible here is the coming together of a number of elements. First is the nature of HIV disease and the particular populations it brings to the medical system; second is the relaxation of institutional oversight by hospital and medical personnel, along with the establishment of specialized, relatively autonomous HIV programs, and third is the desire of these nurses to practice holistically.

This last point may be the most important. For these nurses the practice of their profession has become an expression of their humanity. It may also be the discovery of what being a human being means. Certainly it lets them experience psychological wholeness, because to care for HIV infected patients is to draw on all one's reserves of intelligence, emotional empathy, and physical strength. Cognitive, affective, and physical skills are required all at

the same time.

What HIV disease has done for this particular group of nurses is provide them with a context for vitalization, both personally and professionally. The challenge of HIV disease to a society lulled into complacency lies in making clear the ambiguities and uncertainties of human life. In responding to this challenge, these nurses have found security in insecurity and certainty in uncertainty by relinquishing demands for ultimate answers. Instead they turn to other human beings and find in their commitment to them an answer to what is unknown, what Fernandez (1982) calls the "dark at the bottom of the stairs".

The images these nurses have of nursing embody this answer. To the terror which HIV disease provokes, these nurses reply with images of connection, of people helping other people, of direct person to person contact. These images express what to the individual may be inchoate and unformed. Within the image, of the figure by the bedside, the listening posture, the helping hand, the ideal relationship and the ideal behavior are delineated. These are immortal representations symbolizing mankind's ties to other men and to human history, past and to come. By embracing and validating these images, by using them as guides to action, these nurses defeat death by focusing on that which lives on forever, as long as the human species survives and as long as humanity remembers what being human requires (Lifton 1976). Within these images lies the meaning of their profession and the profession itself is sustained through these images.

The meaning of these images is that life is a unitary experience

of body as well as mind and emotion. Because human life is bodily, it is not eternal, nor can it be painfree. Yet, paradoxically, by accepting that human life must end, a way is found to express what can transcend pain and sorrow, the recognition of another's humanity. And, because this understanding of human life is rooted in an acceptance of the body, it is fitting that it should be expressed in images of human contact.

For the nurses I interviewed, the images they hold of nursing express the assumptions and values of their profession and so provide a basis for concerted action. By holding these images in common, these nurses have a ready made standard against which to judge their own and other's performance. They constitute a cultural frame within which is created an "imagined community" (Anderson 1983). Shared images are the foundation of the community.

It is a community of all those who accept these images. It is a community with stretchable boundaries, a community of people who do not have to live near each other or speak the same language to feel connected. Of the nurses I interviewed, only a few know each other as more than colleagues. The others are acquaintances or strangers. They have diverse backgrounds, diverse educations, diverse experience. But they come together as nurses, nurses committed to a particular kind of nursing, made visible in the images they hold of human connection. To the extent that they give allegiance to these images, these nurses have created a confraternity which transcends differences, differences among themselves and between them and their patients.

In creating a framework within which their patients can be

accepted as they are, these nurses apply the same standards to themselves. The openness and accessibility which they offer to their patients they offer to themselves. For their patients and themselves, the nursing encounter becomes an exercise in freedom, an opportunity to ignore all those distinctions which erect barriers between people, and to focus instead on what draws them together. In honoring their patient's humanity, they honor their own.

They see themselves reflected back from their patients. Their patients act as mirrors, but the reflection is not automatic. These are selective reflections. Nurses can choose to see some things and not others. The nurses in this study choose not to see the poverty, the disarray, the despair, the failure. They choose to see courage and strength. They define the image of themselves that they see in their patients.

The appeal of HIV nursing lies in this mutuality. The nurses in this study practice as they do because they believe in a particular philosophy of care. Their philosophy of care is founded on a moral stance that every human being is worthy, and thus worthy of care. In striving to maintain that code, the nurses in this study learn who they are and who they might become. They experience moments of transcendence when they succeed in making their code a reality. They are transformed through their contact with the transformations of their patients. Thus they experience that wholeness of mind and body which is the essence of healing, illustrating the dictum that what we do for others, we do also for ourselves.

APPENDIX A

INTERVIEW GUIDE:

WHAT DO YOU DO?

HOW DID YOU COME TO NURSE HIV PATIENTS?

DO YOU REMEMBER YOUR FIRST HIV PATIENT?

DO YOU FIND HIV PATIENTS DIFFERENT FROM OTHER PATIENTS?

DO THEY REQUIRE MORE OF YOU?

WHAT ARE THE CHALLENGES OF WHAT YOU DO?

WHAT ARE THE SATISFACTIONS?

DO YOU THINK THERE ARE ANY ETHICAL ISSUES?

**DO YOU GET TO KNOW YOUR PATIENTS WELL? IS THIS SOMETHING YOU
LOOK FOR IN NURSING?**

**DO YOU WORRY ABOUT INFECTION, OR TOXICITY? HOW DO YOU HANDLE
THE WORRY?**

**DO YOU DISCUSS YOUR CONCERNS WITH YOUR COLLEAGUES, ADMIN, DRS,
FRIENDS, FAMILY? WHAT DO THEY SAY?**

DO YOU HAVE ANY PARTICULAR IMAGE OF NURSING? ANY PARTICULAR THING WHICH WHEN YOU THINK OF YOURSELF AS A NURSE YOU PICTURE YOURSELF DOING?

WHAT DO YOU THINK NURSING SHOULD BE?

WOULD YOU RECOMMEND NURSING TO YOUNG PEOPLE TODAY?

DO YOU THINK THERE ARE ASPECTS OF THE DISEASE, OR OF THE PUBLIC'S RESPONSE TO IT, WHICH MAKE TAKING CARE OF HIV PATIENTS MORE DIFFICULT THAN TAKING CARE OF OTHER PATIENTS?

IF YOU WERE ORGANIZING AIDS CARE, WOULD THERE BE ANYTHING YOU WOULD DO DIFFERENTLY?

DO YOU THINK THE PUBLIC, DRS, THE ADMINISTRATION UNDERSTAND THE NURSE'S JOB?

WHAT DO YOU THINK NURSE'S EXPECTATIONS ABOUT NURSING ARE, AND DO SOME OF THEM CONFLICT IN THE CARE OF HIV PATIENTS?

WHAT IS YOUR VIEW OF THE ISSUE OF "WHO IS IN CONTROL?"

WHAT SUSTAINS YOU AS YOU DO THIS WORK?

DO YOU EXPECT TO CONTINUE FOR A WHILE?

APPENDIX B

SURVEY OF NURSES IN AIDS CARE

Responses: number who said this was important; percentage of total in ().
when total is greater than 56, more than one answer given.

What prompted you to become involved in HIV care?

desire to help__39 (69%)__

desire to use skills/talents__33 (58%)__

intrigued with disease__29 (51%)__

personal contact with disease__13 (23%)__

attractive job__11 (19%)__

other: AIDS unit opened__6 (10%); commitment to community __3 (5%)__;
wanted change __3 (5%)__

What are the challenges of what you do?

patients' emotional needs__48 (85%)__

comforting patients and families__39 (60%)__

copng with patient deterioration: physical__32 (57%)__mental__33 (58%)__

patients' clinical instability__32 (57%)__

working with colleagues who do not share your philosophy of care__32 (57%)__

copng with death__32 (57%)__

sustaining patients' hope__31 (55%)__

overcoming bureaucratic obstacles__31 (55%)__

social stigma of disease__26 (46%)__

maintaining your own emotional balance__24 (42%)__

working within limitations of care__20 (35%)__

persevering through difficulties and failure__16 (28%)__
 coping with contagion__8 (14%)__
 other: keeping up with current knowledge__2 (3%)__; placing
 terminally ill patients and children of HIV patients in hospices
 and homes__2 (3%)__; reaching non-compliant patients __2
 (3%)__; disdain from colleagues and friends __2 (3%)__.

What are the satisfactions?

teaching and counseling_43 (76%)__
 involvement in important work__42 (75%)__
 establishing a personal connection with patients__41 (73%)__
 being able to use every kind of nursing skill__36 (64%)__
 meeting the challenge of clinical care__32 (57%)__
 working with like-minded colleagues__27 (48%)__
 other: helping patients face death and unfinished business__3 (5%)__;
 facing the possibility of death for myself __2 (3%);
 opportunity to be gentle and compassionate __1 (2%).

Do you meet any ethical issues in your work?

access to treatment/drugs__35 (63%)__
 DNRs (Do Not Resuscitate Orders)__30 (53%)__
 termination of treatment__29 (51%)__
 recognizing the limits of hi-tech medical care__29 (51%)__
 maintaining confidentiality__28 (50%)__
 toxic medication_25 (44%)__
 notifying partners/family members__20 (35%)__
 encountering suicide requests__19 (32%)__
 pregnancy decisions by HIV+ patients_15 (26%)__
 other: physicians and institutions uninterested in care of patients__3

(5%)__; cost of care and medication__1 (2%)__; conflicts between patient's wishes and their family's__1 (2%)__; fear of HIV patients in at risk population_ 1 (2%)__.

What keeps you going?

pleasure from patient contact__45 (80%)__
feeling that work is meaningful/needed__44 (78%)__
personal growth__36 (64%)__
"making a difference"__36 (64%)__
commitment to providing healthcare for all__36 (64%)__
helping others__30 (53%)__
clinical interest__30 (53%)__
having interests outside work__23 (40%)__
feeling of identification__11 (19%)__
support from family and friends__11 (19%)__
other: belief in God __1 (2%)__; working with like-minded colleagues__1 (2%); appreciation from patients __1 (2%)__.

Do you have a support group at work? Yes_29 (51%)__No__27 (48%)__
if No, would you like one? Yes_11 (19%)_No_9 (16%)__ No Ans__7 (12%)__.

How long do you expect to be in HIV care?

1-3 years__4 (7%)
3-5 years__5 (8%)
5+ years__2 (3%)
Indefinitely _30 (53%)
Not Sure____12 (20%)

Are you concerned about becoming infected through patient contact?

HIV_14 (25%)__

TB__27 (48%)__

Pneumonia__3 (5%)__

Other: Hepatitis__4 (6%)__Salmonella__1 (2%)__.

How do you think about death?

a final end_9 (16%)__

a passing to another kind of existence__39 (69%)__

other: peace and fulfillment__4 (7%)__; union with God__2 (3%)__.

no response:__2 (3%)__

When you think of being a nurse, does a particular image come to mind, such as:

listening as a patient talks,__42 (74%)__

talking with a patient, __39 (69%)__

giving physical care,__31 (55%)__

sitting by a patient's bed, holding his/her hand, __27 (48%)__

walking arm and arm with the patient,__20 (35%)__

dispensing medications,__20 (35%)__

other: being there for patients__11 (19%)__; conferring with doctors,

other healthcare providers__3 (6%)__.

Has HIV affected your relations with doctors?

improved collaboration and collegiality__38 (67%)__

increased your autonomy__39 (69%)__

brought you into conflict__24 (42%)__

if so, on what issues: treatment goals__13 (23%)__; death/DNRs__5

(9%)__; incompetence__3 (5%)__; homophobia__3 (5%)__;

confidentiality__1 (2%)__; issues of care for women and

children__1 (2%)__.

how do you handle them: information gathering__12 (21%)__;

assertiveness / confrontation__6 (10%)__; discussion and
advocacy__9(16%)__.

Has HIV affected your relations with officialdom/bureaucrats/administrators?

No Difference:__16 (28%)__.

Positively__6 (10%)__.

Negatively__22 (39%)__

No Ans__12 (21%)__.

If so,

please describe:

positive effect: openness and respect__5 (9%)__; forced accountability
and ethical decision-making__1 (2%)__.

negative effect: pressure to shortchange patients in the name of
efficiency__13 (23%)__; insensitivity to patients'
needs__9 (16%)__; difficulty getting through red tape__4
(8%)__; disagreements over staffing levels__11 (19%)__;
discrimination against HIV patients__3 (5%)__; "playing
games with people's lives"__1 (2%)__.

What prompted you to become a nurse?

desire to take care of the sick__29 (51%)__

always wanted to be a nurse__23 (40%)__

ideal of service__17 (30%)__

the many different careers in nursing__16 (28%)__

interest in medicine__15 (26%)__

job security__12 (21%)__

one of few career choices available__10 (17%)__

nurses in family__7 (12%)__

other: parental pressure__3 (5%)__; interest in women's

health__1 (2%)__; a "people" profession__1 (2%)__;

army experience__1 (3%)__; no particular reason__4 (8%)__.

Were you influenced in choosing nursing by books about nurses, such as
biographies of

Florence Nightingale __8 (14%)__

Clara Barton __8 (14%)__

Movies__2 (3%)__

TV shows__3 (5%)__

Others: Biographies of Lillian Wald__2 (3%)__; Rose Hawthorne__1

(2%); Mary Anne Bickerdyke__1 (2%)__.

Cherry Ames novels:__5 (9%)__

Would you recommend nursing to young people today?

No__13 (23%)__

Yes__46 (82%)__

Why "No": long hours and hard work__6 (10%)__; low status, low

salary__4 (7%)__; high stress__2 (3%)__; little power__2 (3%)__;

not creative__1 (2%)__; little appreciation__1 (2%)__.

Why "Yes": personal growth and satisfaction__11 (19%)__; variety__9

(16%)__; intellectual excitement__5 (8%)__;

chance to be creative and caring __ 5 (8%)__; opportunity to

make changes__4 (7%)__; economic security __4 (7%)__;

worthwhile "real world" profession__3 (6%)__;

improving salaries__3 (6%)__.

Demographic Information:

Age:

20-30__0__

30-40__30 (53%)__

40-50__19 (32%)__

50+__7 (12%)__

No Ans:__0__

Years of Nursing Experience:

1-3 years__0__

3-5 years__3 (2%)__

5-10 years__8 (14%)__

10-15 years__20 (35%)__

15-25 years__15 (26%)__

25+__9 (16%)__

No Ans:__1 (2%)__

Degree(s):

Diploma__8 (14%)__

Associate__5 (8%)__

B.A.__19 (32%)__

B.S.__24 (42%)__

M.S./ M.A._ 22 (39%)__

M.A./M.S. in progress__4 (7%)__

Ph.D.__2 (3%)__

No Ans:__4 (7%)__

Current Job:

Staff Nurse__10 (17%)__

Clinician__20 (35%)__

Co-ordinator/Director__8 (14%)__

Educator__6 (10%)__

No Ans:__12 (21%)__

Years in Current Job:

0-1 year__9 (16%)__
1-3 years__17 (30%)__
3-5 years__10 (17%)__
5-10 years__6 (10%)__
10+_____2 (3%)__
No Ans:_____12 (21%)__

Patient Population:

Men: 100%__1 (2%)__
90-99%__15 (26%)__
80-90%__4 (7%)__
70-79%__6 (10%)__
60-69%__7 (12%)__
50-59%__7 (12%)__
40-49%__2 (3%)__
30-39%__0__
20-29%__0__
10-19%__0__
1-9%__0__
0%__5 (8%)__

Women: 100%__2 (3%)__
90-99%__1 (2%)__
80-89%__0__
70-79%__0__
60-69%__1 (2%)__
50-59%__4 (7%)__
40-49%__6 (10%)__

30-39%__5 (8%)__
 20-29%__7 (12%)__
 10-19%__14 (25%)__
 1-9%__7 (12%)__
 0%__4 (7%)__

Children: 100%__1 (2%)__
 90-99%__1 (2%)__
 80-89%__1 (2%)__
 70-79%__0__
 60-69%__0__
 50-59%__0__
 40-49%__0__
 30-39%__0__
 20-29%__1 (2%)__
 10-19%__6 (10%)__
 1-9%__3 (5%)__
 0%__38 (67%)__

No Ans: 5 (8%)

White: 100%__0__
 90-99%__6 (10%)__
 80-89%__1 (2%)__
 70-79%__2 (3%)__
 60-69%__5 (8%)__
 50-59%__3 (5%)__
 40-49%__5 (8%)__
 30-39%__3 (3%)__
 20-29%__14 (25%)__

10-19%__9 (16%)__
 1-9%__5 (8%)__
 0%__0__
Black: 100%__0__
 90-99%__1 (2%)__
 80-89%__0__
 70-79%__2 (3%)__
 60-69%__3 (5%)__
 50-59%__9 (16%)__
 40-49%__11 (19%)__
 30-39%__9 (16%)__
 20-29%__8 (14%)__
 10-19%__2 (3%)__
 1-9%__6 10%)__
 0%__1 (2%)__
Hispanic: 100%__0__
 90-99%__0__
 80-89%__0__
 70-79%__1 (2%)__
 60-69%__0__
 50-59%__4 (7%)__
 40-49%__15 (26%)__
 30-39%__10 (17%)__
 20-29%__12 (21%)__
 10-19%__4 (7%)__
 1-9%__7 (12%)__
 0%__0__

Other: 100%__0__
 90-99%__0__
 80-89%__0__
 70-79%__0__
 60-69%__0__
 50-59%__0__
 40-49%__0__
 30-39%__0__
 20-29%__0__
 10-19%__2 (3%)____
 1-9%__4 (7%)____
 0%__46 (82%)__

No Ans:__ 4 (7%)__

Homosexual: 100%__0__
 90-99%__7 (12%)__
 80-89%__3 (5%)__
 70-79%__3 (5%)__
 60-69%__1 (2%)__
 50-59%__4 (7%)__
 40-49%__8 (14%)__
 30-39%__5 (8%)__
 20-29%__5 (8%)__
 10-19%__4 (7%)__
 1-9%__2 (3%)__
 0%__5 (8%)__

Drug Users: 100%__1 (2%)__
 90-99%__4 (7%)__

	80-89%__1 (2%)__
	70-79%__6 (10%)__
	60-69%__6 (10%)__
	50-59%__5 (8%)__
	40-49%__3 (5%)__
	30-39%__4 (7%)__
	20-29%__4 (7%)__
	10-19%__5 (8%)__
	1-19%__7 (12%)__
	0%__1 (2%)__
Other:	100%__0__
(partner of drug user;	90-99%__1 (2%)__
heterosexual;	80-89%__0__
blood transfusion)	70-79%__0__
	60-69%__1 (2%)__
	50-59%__0__
	40-49%__1 (2%)__
	30-39%__3 (5%)__
	20-29%__1 (2%)__
	10-19%__6 (10%)__
	1-9%__6 (10%)__
	0%__28 (50%)__
No Ans:	__9 (16%)__

REFERENCES CITED

- Agan, R. David 1987 "Intuitive Knowing as a dimension of nursing" *Advanced Nursing Science* 10 (1) 63-70
- AIDS ALERT 1992 "CDC's expanded AIDS case definition sparks controversy" American Health Consultants publication Volume 7 #5: 65-71
- Allan, Janet D. and Beverly A. Hall 1988 "Challenging the focus on technology: A Critique of the medical model in a changing health care system" *Advanced Nursing Science* 10(3) 22-34
- Anderson, Benedict 1983 Imagined Communities London: Verso
- Armstrong, Donald M.D. 1983 "Viral Infections" in The AIDS Epidemic Kevin Cahill, M.D. ed. NY: St. Martin's Press
- Baer, Ellen 1991 "Further Thoughts on 'the Feminist Disdain for Nursing'" paper delivered October 30,1991 University of Virginia Health Sciences Center
- Bartlett, Lawrence 1990 "Financing Health Care for Persons with AIDS: Balancing Public and Private Responsibilities" in AIDS and the Health Care System Lawrence Gostin ed. New Haven: Yale University Press
- Bayer, Ronald 1990 "Perinatal Transmission of HIV infection: The Ethics of Prevention" in AIDS and the Health Care System Lawrence Gostin ed. New Haven: Yale University Press
- Benoit, Hubert 1955 The Supreme Doctrine: Psychological Studies in Zen Thought NY: Pantheon Books
- Belenky, Mary Field, B. M. Clinchey, N. R. Goldberger and J. M. Tarule 1986 Women's Ways of Knowing: Development of Self, Voice and Mind NY: Basic Books
- Berger, Peter 1990 (1969) A Rumor of Angels: Modern Society and the Discovery of the Supernatural NY: Doubleday
- Berger, Peter 1990 (1967) The Sacred Canopy NY: Doubleday
- Berger, Peter and Brigitte Berger 1974 The Homeless Mind NY: Random House

- Boddy, Janice 1989 Wombs and Alien Spirits Madison: University of Wisconsin Press
- Brandt, Allan M. 1985 No Magic Bullet: A Social History of Venereal Disease in the United States since 1880 NY: Oxford University Press
- Brown, William, J. and James F. Donohue 1970 Syphilis and Other Venereal Diseases Cambridge: Harvard University Press
- Bruner, Jerome 1969 On Knowing: Essays for the Left Hand Cambridge: Harvard University Press
- Camus, Albert 1948 The Plague translated by Gilbert Stuart NY: A.A. Knopf
- Cantwell, Alan 1983 AIDS, the Mystery and the Solution Los Angeles: Aries Rising Press
- Cassell, Joan 1991 Expected Miracles: Surgeons at Work Philadelphia: Temple University Press
- Center for Disease Control Morbidity and Mortality Weekly Reports June 5, 1981
Supplement, September 4, 1987
- Chang, Sophia et al. 1992 "The New AIDS Case Definition: Implications for San Francisco" JAMA 267:973-975.
- Crapanzano, Vincent 1985 Waiting: The Whites of South Africa NY: Random House
- Crosby, Alfred 1989 America's Forgotten Pandemic: The Influenza of 1918 Cambridge: Cambridge University Press
- Downes, Joanne 1988 "Nursing in the Time of Plague: A Study of Motivational Factors in Nursing from the Black Death to AIDS" unpublished paper: Ph.D. program Columbia Teachers' College
- Dumpson, J.R., et al 1989 "AIDS and minorities: strategies for prevention" International Conference on AIDS, January 4-9 5:818 (abstract no. ME023)
- Eliade, Mircea 1954 The Myth of the Eternal Return NY: Pantheon Books

- Fernandez, James 1982 "The Dark at the Bottom of the Stairs" in On Symbols in Anthropology: Essays in Honor of Harry Horjer Jacques Maquet, Milton Singer, Melford Spiro eds. Undera Publication of the UCLA Department of Anthropology Malibu, CA.
- Fiedler, Leslie 1988 "Images of the Nurse in Fiction and Popular Culture" in Images of Nurses Anne Hudson Jones ed. Philadelphia: University of Pennsylvania Press
- Foege, William M.D. 1983 "The National Pattern of AIDS" in The AIDS Epidemic Kevin Cahill, M.D. ed. NY: St. Martin's Press
- Fox, Daniel M. and Emily H. Thomas 1990 "The Cost of AIDS: Exaggeration, Entitlement, and Economics" in AIDS and the Health Care System Lawrence Gostin ed. New Haven: Yale University Press
- Fox, Renee C., Linda H. Aiken and Carla M. Messikomer 1990 "The Culture of Caring: AIDS and the Nursing Profession" Milbank Quarterly Vol 68, Supplement 2
- Furth, Hans 1987 Knowledge as Desire: an essay on Freud and Piaget NY: Columbia University Press
- Gadow, Sally 1980 ""Existential Advocacy: Philosophical Foundation of Nursing" Nursing Images and Ideals Stuart F. Spicker, ed. NY: Springer Publishing
- Gee, Gayling 1989 "Nurse Attitudes and AIDS" in Public and Professional Attitudes towards AIDS Patients David E. Rogers and Eli Ginzberg eds. Boulder: Westview Press
- Geertz, Clifford 1983 Local Knowledge: Further Essays in Interpretive Anthropology NY: Basic Books
- Geertz, Clifford 1973 The Interpretation of Cultures NY: Basic Books
- Good, Byron 1988 "Learning Medicine: The Construction of Medical Knowledge at Harvard Medical School" paper prepared for the Wenner Gren Foundation conference No. 106 Analysis in Medical Anthropology held at Hotel do Guincho, Lisbon, Portugal March 5-13, 1988
- Gorman, E. Michael 1986 "The AIDS Epidemic in San Francisco:

- Epidemiological and Anthropological Perspectives" in Anthropology and Epidemiology Craig R. James, ed. Dordrecht, Holland:D. Reidel Publishers
- Gwartney, Daniel L. 1992 "PWAs in the Long Term Care Facility" AIDS Patient Care February 1992 Vol 6 #1
- Harawi, Sami J. and Carl J. O'Hara 1989 Pathology and Pathophysiology of AIDS and HIV-related Diseases London:Chapman and Hall
- Heimhoff, Steve and Julia Sommer 1991 "Is the HIV Theory All Wrong?" CalReport #8:1 Fall
- Henderson, Virginia and Bertha Harmer 1939 Textbook of the Principles and Practice of Nursing New York: Macmillan
- Henderson, Virginia 1990 "Nursing in America: A History of Social Reform" New York:NLN Video
- Jackson, Michael 1988 "In the Thrown World: Destiny and Decision in the Thought of Traditional Africa: in Choice and Morality in Anthropological Perspective Albany: SUNY Press
- James, William 1985 Varieties of Religious Experience Cambridge: Harvard University Press
- Jagger, Alison 1989 "Love and Knowledge: Emotion in Feminist Epistemology" in Gender/Body/Knowledge Alison Jagger, ed. NJ: Rutgers University Press
- Johnson, Tom 1991 Anthropology Newsletter December Vol. 32#9
- Jones, Kenneth L., Louis W. Shainberg, and Curtis O. Boyer 1974 VD NY: Harper & Row
- Jonsen, Albert R. 1990 "The Duty to Treat Patients with AIDS and HIV Infection" in AIDS and the Health Care System Lawrence Gostin ed. New Haven: Yale University Press
- Karpen, Maxine 1992 "Post-Exposure Management" AIDS Patient Care April 1992 Vol 6 #2
- Karpen, Maxine 1992 "Are Medical Residents Being Trained in AIDS Care?" AIDS Patient Care 1992 Vol 6 #2

- Katz, Robert 1963 Empathy: Its Nature and Uses London: Collier MacMillan
- Keller, Evelyn Fox 1985 Reflections on Gender and Science New Haven: Yale University Press
- Killip, Thomas 1989 "Hospitals in NYC: A System under Stress" in Public and Professional Attitudes Towards AIDS Patients David E. Rogers and Eli Ginzberg eds. Boulder:Westview Press
- Langer, Suzanne 1963 Feeling and Form NY:Scribner
- Levine, Carol 1990 "In and Out of the Hospital" in AIDS and the Health Care System Lawrence Gostin ed. New Haven:Yale University Press
- Lifton, Robert Jay 1979 The Broken Connection: On Death and the Continuity of Life New York: Simon and Schuster
- 1976 The Life of the Self NY: Simon & Schuster
- Louria, Donald B. M.D. 1983 "Bacterial and Mycotic Infections" in The AIDS Epidemic Kevin Cahill M.D., ed. NY: St. Martin's Press
- Ludmerer, Kenneth M. 1989 "Patients Beyond the Pale" in Public and Professional Attitudes Towards AIDS David E. Rogers and Eli Ginzberg eds. Boulder: Westview Press
- Maquet, Jacques 1986 The Aesthetic Experience: An Anthropologist looks at the Visual Arts Yale University Press: New Haven
- Malson, Lucien 1972 Wolf Children and the Problem of Human Nature NY:Monthly Review Press
- Mauss, Marcel 1979 Sociology and Psychology: Essays London: Routledge and Kegan Paul
- Melosh, Barbara 1982 The Physician's Hand: Nurses and Nursing in the 20th century Philadelphia: Temple University Press
- Merleau-Ponty, Maurice 1969 Eye and Mind: The Essential Writings of Merleau-Ponty A. L. Fisher ed. NY:Harcourt, Brace & World

- Murray, Thomas H. and Gretchen M. Aumann 1987 "Ethical Issues in AIDS" in AIDS: Facts and Issues Victor Gong and Norman Rudnick, eds. NJ: Rutgers University Press
- NYC AIDS Surveillance Update Second Quarter 1991 Issued July 31, 1991
- NYC Department of Health Library for AIDS Resources August 1991 Monthly Packet for Community Based and Citywide Organizations; Bureau of HIV Program Services
- Novick, L. F. et al 1991 "Newborn Seroprevalence Study: Methods and Results" American Journal of Public Health 81:15-21 May '91 Supplement
- Norbeck, Edward 1970 "Changing Japan: Field Research" in Being an Anthropologist: Fieldwork in Eleven Cultures George Spindler, ed. NY: Holt, Rinehart & Winston
- Patton, Michael Quinn 1990 Qualitative Evaluation and Research Methods Newbury Park, Ca: Sage
- Payer, Lynn 1988 Medicine and Culture: Varieties of Treatment in the US, England, West Germany and France NY: Holt
- Perin, Constance 1988 Belonging in America Madison: University of Wisconsin Press
- Pettigrew, Eileen 1983 The Silent Enemy: Canada and the deadly Flu of 1918 Saskatoon, Saskatchewan: Modern Press
- Polanyi, Michael 1962 Personal Knowledge Chicago: University of Chicago Press
- Reik, Theodor 1948 Listening with the Third Ear NY: Farrar, Straus & Co.
- Reverby, Susan 1987 Ordered to Care Cambridge: Cambridge University Press
- Sanday, Peggy Reeves 1983 "The Ethnographic Paradigm(s)" in Qualitative Methodology Van Maanen, ed. Newbury Park: Sage
- Sarter, Barbara 1987 "Evolutionary Idealism: a philosophical foundation for holistic nursing theory" Advanced Nursing

Science 9(2) 1-9

Schwarz, M. Roy 1989 "Physicians' Attitudes towards AIDS" in Public and Professional Attitudes towards AIDS Patients David E. Rogers and Eli Ginzberg eds. Boulder:Westview Press

Scitovsky, Anne 1986 "Medical Care Costs of Patients with AIDS in San Francisco" Journal of the American Medical Association 256:3103-6

Sloand, Elaine et al 1991 "HIV Testing State of the Art" Journal of the American Medical Association 266:2861-2866

Smith, Jane 1990 Patenting the Sun: Polio and the Salk Vaccine NY: William Morrow

Spiegelberg, Herbert 1976 The Phenomenological Movement The Hague, Netherlands: Martinus Nyhoff

Starr, Paul 1982 The Social Transformation of American Medicine NY: Basic Books

Thomas, P. A. "The NYC Perinatal HIV Transmission Study" by the NYC Department of Health V International Conference on AIDS Montreal, Canada June 8, 1989 Abstract Th.A.O.7

Tronto, Joan C. 1990 "Woman and Caring: What can Feminists Learn about the Morality from Caring?" in Gender/Body/Knowledge Alison Jagger, ed. NJ:Rutgers University Press

Vladeck, Bruce C. 1989 "The Economics of a Caring Approach" in Public and Professional Attitudes towards AIDS Patients David E. Rogers and Eli Ginzberg, eds. Boulder:Westview Press

Van Maanen 1983 "Reclaiming Qualitative Methods for Institutional Research: A Preface" in Qualitative Methodology Newbury Park: Sage

Watts, Fraser and Mark Williams 1988 The Psychology of Religious Knowing Cambridge:Cambridge University Press

Weil, Simone 1973 (1951) Waiting for God NY:Harper & Row