INFORMATION TO USERS

The most advanced technology has been used to photograph and reproduce this manuscript 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 9020759

Death work: Staff perspectives on the care of terminally ill patients in an acute care hospital

Goodman, Harriet Gouline, D.S.W.

City University of New York, 1990

Copyright ©1990 by Goodman, Harriet Gouline. All rights reserved.

U·M·I
300 N. Zeeb Rd.
Ann Arbor, MI 48106

DEATH WORK:
STAFF PERSPECTIVES ON THE CARE OF TERMINALLY ILL PATIENTS IN AN ACUTE CARE HOSPITAL

by

Harriet Goodman

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

1990

COPYRIGHT 1990 BY HARRIET GOODMAN

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

1/2/90
Date

Chairman of Examining Committee

1/2/90
Date

Executive Officer

Irwin Epstein

Judith Lorber

Mildred Mailick

Supervisory Committee

The City University of New York

Abstract

DEATH WORK:
STAFF PERSPECTIVES ON THE CARE OF TERMINALLY ILL PATIENTS
IN AN ACUTE CARE HOSPITAL

by

Harriet Goodman

Advisor: Dr. Irwin Epstein

This dissertation is a qualitative study of the perspectives of doctors, nurses, and social workers on terminally ill patients in their care. The methods used for this study were participant observation and focused interviews with professionals about dying patients whom they identified as "difficult to manage." Fifteen patients were suggested, nine of whom had metastatic cancer and six of whom had AIDS. Eight physicians, ten nurses, and thirteen social workers were formally interviewed. The data for this study were collected in the mid-1980's at a prestigious medical center in a large urban city. The investigator was a research assistant with a medical service providing symptom management for dying patients in this hospital.

A "Typology of Ideal, Routine, and 'Toxic' Patients" was developed based on qualitative data gathered from this study. It describes three terminally ill patient types in relation to professional needs for cure or symptom amelioration, routinized work, and personal gratification. "Ideal" patients exceeded workers' expectations for response. "Routine" patients conformed

to normative expectations and presented conventional problems. "Toxic" patients disrupted routines, had unattractive personal or disease characteristics, and questioned professional authority.

Merton's theory of anomie (1968) was used to analyze professional responses associated with death work. Doctors and nurses were most frustrated when their curative interventions failed. Social workers found more goal congruity with death work and were frequently successful in supportive interventions with dying patients and their families.

AIDS patients posed different problems for professionals than metastatic cancer patients. All professional groups were concerned about HIV exposure. The mass media were a major source of information even for highly educated professionals. Homophobic and punitive responses to AIDS patients were frequently observed and frankly expressed by several informants. Some staff stated that increased contact diminished homophobia. As with all dying patients, expressions of gratitude for staff efforts and/or heroic behavior earned AIDS patients and families the label of "ideal." The exploratory nature of this study, limited sample, and single study site make these findings only suggestive. Nevertheless, findings from this study point to the need for support of professional work with the dying, particularly in an environment of increasing numbers of AIDS patients.

ACKNOWLEDGMENTS

Writing a dissertation is a lonely endeavor. Unlike most work activities I have performed in my life, this project seemed uniquely my own. During the course of this study I was separated from the pleasures of collegial interaction with social workers and found myself working with physicians, nurses, and basic scientists. The availability and support of my project advisors made the work bearable. Their communication from outside the parochial world of biomedical research helped me to make sense of this environment and ultimately enabled me to use the experience productively.

Without their encouragement and enthusiasm for my work, I could not have managed to keep my eye on my own vision. Irwin Epstein and Judith Lorber took me by the hand through both scholarly and personal trials, and I thank them for their intelligence and wisdom and the generosity with which they shared both. Mildred Mailick's insightful reading of this study added considerable clarity to the final product.

As a member of the Supportive Care Team, I worked with dedicated medical and nursing professionals, committed to the quality of life of their patients and willing to teach others about making the end of life tolerable. Watching their devotion and discipline as they proceeded with this mission was inspirational. Their insight into the life of this imperfect institution reflected

accumulated years of wisdom. I was privileged to work alongside them. My generous thanks to Dr. Henry Erle, Dr. Marcus Reidenberg, Dr. Rosanne Leipzig, and Dr. Oscar Laskin. An especially fond personal thank you to Dr. Gari Gray, the stellar clinical nurse specialist whose candor and intelligence helped me unravel the complexities of hospital life.

Throughout my work on this project, I was blessed to come home to my two vigorous and lively sons, Michael and David. As I wormed my way along the path to becoming an "idea doctor," their optimism made it all worthwhile.

TABLE OF CONTENTS

ABSTRACT.. iv

ACKNOWLEDGMENTS... vi

Chapter

I. INTRODUCTION AND REVIEW OF THE LITERATURE: THE DEATH WORK OF PROFESSIONAL HEALTH WORKERS......... 1

Introduction.. 1
Review of the Death and Dying Literature: Introduction.................................. 3
Structural Perspectives on Death and Dying....... 6
Hospital Structure and the Needs of the Dying.................................. 7
Disclosure of a Terminal Diagnosis............ 12
Attitudes of Health Professionals About Terminal Care................................ 15
Avoidance of Terminally Ill Patients by Care Givers................................ 15
Attitudes towards Withholding Treatment or Prolonging Life.......................... 19
Health Professional Stress in Terminal Care........ 21
Health Workers and AIDS: Review of the Literature. 24
Background.................................. 24
Problems in Social and Psychological Investigations of AIDS...................... 26
The Fear of Contagion: Viral and Social Contamination.............................. 29
The Psychological Impact of AIDS on Health Workers............................. 37
Conclusion.. 39

II. PROJECT SITE: DESCRIPTION OF THE SETTING............. 41

Introduction.. 41
The Hospital Medical Complex....................... 43
General Description.......................... 43
Medical Training Program...................... 45
Organization of Care in the Teaching Hospital. 46
Organizational Culture........................ 49
The Social Service Department...................... 53
General Description.......................... 53
The New Social Service Administration......... 55
Department in Transition...................... 56
Expanded Staff Development.................... 58
Autonomous Case Finding....................... 59
Discharge Planning............................ 62

The Department of Nursing........................... 63
Changes in the Context of Health Care.............. 65
Diagnostic Related Groups..................... 67
The Impact of AIDS................................ 70
Background.................................... 70
The Impact of AIDS on Health Professionals.... 72
The Hospice Legislation: Culmination of the Death
Death Awareness Movement......................... 74
The Hospice Movement in The United States.... 74
Developing Guidelines for Applying
Life Sustaining Treatments................. 76
The Author's Position in the Setting.............. 78
The Author's Relationship to the
Supportive Care Service..................... 79
The Decline of the Supportive Care Service.... 81
Opportunities for Observing Terminal Care..... 83
Supports in Study Implementation.............. 83
Problems in Implementation.................... 85
Conclusion.. 86

III. METHODOLOGY.. 88

Introduction...................................... 88
Advantages of Qualitative Methods for this Study... 89
Grounded Theory................................... 92
My Role as Researcher............................. 95
Project Approval and Staff Cooperation............ 101
Institutional Approval........................ 101
Social Work and Nursing Approval.............. 103
Involving Physician Participation............. 107
Data Collection................................... 108
Observations.................................. 108
Focused Interviews and Chart Review........... 109
The Questionnaire............................. 115
Data Analysis and Feedback........................ 117
Conclusion.. 118

IV. IDEAL, ROUTINE, AND "TOXIC" PATIENTS: PATIENT TYPES
IN TERMINAL CARE.................................. 120

Introduction...................................... 120
Good and Bad Patient Types: A Review of the
Literature..................................... 121
Medical Views of Problem Patients............. 125
Sociological Perspectives on the "Bad" Patient. 127
A Typology of Patient Types and Health Professional
Needs: "Toxic", Routine, and Ideal Terminally
Ill Patients.................................. 131

Illness Trajectory.................................. 139
Personal and Disease Characteristics: Forgiven and Unforgiven Patients.......................... 141
Conclusion.. 146

V. "TOXIC" DIMENSIONS: TERMINALLY ILL CANCER PATIENTS. 148

Introduction...................................... 148
Technological Impact: Death as Failure............ 151
The Dying Patient in the Tertiary Care Hospital................................. 151
"Toxic" Dimensions for House Staff............ 154
"Toxic" Dimensions for Nurses................. 155
"Toxic" Dimensions for Social Workers......... 157
"Toxic" Patient Types............................. 159
Patient and Family Involvement................ 159
Patients Who Reject Doctor's Recommendations.. 161
Patients Who Seek Non-Traditional Care........ 164
Sources of Disrupted Routines..................... 166
Obstructing Worker Activities................. 166
Routines for Disclosing a Patient's Prognosis. 170
The Impact of the Environment on Terminal Care Routines...................... 175
Ideal Terminally Ill Patients..................... 178
Personal Gratification and the Terminally Ill Patient................................ 178
Patient Identification: The Heroic Patient... 180
The Remarkable Remission...................... 182
Conclusion.. 185

VI. WORKING WITH AIDS PATIENTS: "TOXIC" DIMENSIONS FOR HEALTH WORKERS.................................. 186

Introduction...................................... 186
Ideal, Routine, and "Toxic" AIDS Patients.......... 187
Technological Impact on an Inevitably Fatal Disease.................................... 187
The Impact of AIDS on Physicians.............. 188
The Impact of AIDS on Nurses.................. 190
The Impact of AIDS on Social Workers.......... 192
Multiple Failure for All Professional Groups....... 195
AIDS and the Disruption of Established Work Routines.. 200
Professional Work Routines.................... 200
AIDS Impact on Work Routines.................. 201
Fears of Contagion........................... 204

Problems of Identification: Affective Responses to AIDS Patients.................................. 206
Homophobic Reactions to AIDS Patients......... 208
The Impact of the Media on Health Professionals.............................. 212
Research Issues and Clinical Practice with AIDS Patients.................................... 214
Conclusion.. 218

VII. UNDERSTANDING HEALTH PROFESSIONALS' RESPONSES TO DEATH WORK... 219

Introduction.. 219
Merton's Theory of Anomie......................... 221
Professional Responses to the Anomie of Terminal Care... 224
Responses of Nurses........................... 225
Responses of Attendings and House Staff....... 230
Responses of Social Workers.................. 233
The Supportive Care Service as Rebellion........... 237
Conclusion.. 238

VIII. CONCLUSIONS AND PRACTICE IMPLICATIONS............ 240

Introduction.. 240
Review of the Study................................ 241
Changes in Terminal Care........................... 244
Comparing the Death Work of Doctors, Nurses, and Social Workers.................................. 246
Comparing Professional Work with AIDS Patients and Metastatic Cancer Patients....................... 249
Recent Developments in the AIDS Epidemic........... 254
Strategies for Supporting the Works of Professional Caregivers to the Dying.......................... 256
Areas for Further Study............................ 259
Conclusion.. 261

APPENDICES

1. Supportive Care Service Flier...................... 262

2. Institutional Cor ent Letters...................... 265
   Human Rights Committee Approval Request........... 266
   Nursing Department Approval Request Memo.......... 267

3. Social Work Staff Memos............................ 269

4. Data Collection Forms.............................. 272

5. Triangulated Interview Format...................... 275

BIBLIOGRAPHY.. 278

LIST OF TABLES

1. Weekly Meeting Schedule for Clinical Pharmacology and Supportive Care Services............................ 110

2. Diagnosis, Sex, Age and Referral Source of Study Patients...................................... 112

3. Working Typology of Indicators Illustrating Types of Problems with Dying Patients........................ 113

4. Typology of Terminally Ill Patient Types: Ideal, Routine, and Toxic Patients......................... 132

CHAPTER ONE

INTRODUCTION AND REVIEW OF THE LITERATURE
THE DEATH WORK OF PROFESSIONAL HEALTH WORKERS

Introduction

Doctors, nurses, and social workers in hospitals strive to cure and rehabilitate patients. Unfortunately, and despite their best efforts, they must also work with patients who are dying. Because death is an event which has moved in recent years from the home to hospitals and nursing homes, health providers have the most intimate and frequent contact with dying people.

Health workers, more than any other group in our society, shepherd us to our death. In spite of technical progress which often provides care givers the satisfaction of seeing patients restored to good health, professional health workers also witness the limits of their capacity to affect the boundaries of our invincibility over death. At the same time that health professionals have the greatest stake in affirming the power of healing, they must also confront its limits. Since more people presently die from chronic illness rather than acute illness, the process of dying is more protracted in contemporary medical practice than it has been in the past. The experience of dying is

extended for patients, their families, and for health care providers as well.

Hospital professionals often state that their motivations to work in health care are altruistic. They express a desire to cure patients and return them home. Death is the persistent reminder of their ultimate helplessness with patients and for themselves. This frustration makes their role as care givers to the dying particularly poignant. An additional burden is the fact that the hospitals in which they work are organized to cure patients. These institutions do not support death work. Consequently, hospital staff who work on the line with patients whose illnesses cannot be successfully treated find their difficult work further complicated by a dramatic disparity of goals. Indeed, the fact that the hospital is structured to accomplish patient cure means that supports for the staff when a cure is impossible are limited or entirely absent.

This study of the responses of health professionals to their work with dying patients describes the experience of terminal care from the perspective of medical doctors, nurses, and social workers in an acute care hospital. Using data from observation of their interactions with the dying and interviews with professional staff about their problems and successes with dying patients, I will examine the strains in this work for the care givers and their responses to its problems. Most clearly, problems center on the

perceived failure of professionals to provide a successful outcome for patients, since dying patients undermine the health care worker's sense of competence. Several other problems for staff in such a unit that are sources of strain for health care providers will be explored.

This study was undertaken in a tertiary care acute care hospital. In such settings, the tensions between hoped-for and actual outcomes are particularly stark, for in most cases, no medical intervention will eventuate in a cure. Many patients die. Patients frequently came to this hospital at the end of a long illness trajectory. Described to prospective patients as the "Mecca" by some health professionals connected with this institution, patients come seeking medical intervention often not available from their local hospitals and physicians. Yet even the most modern and up-to-date equipment and the most sophisticated technical know-how can prove inadequate. The staff, working in a setting which accentuates the most profound and technically competent dimensions of the human experience -- the capacity to heal and mend -- have to contend with their institutional, professional, and personal helplessness each time a patient dies.

Review of the Death and Dying Literature: Introduction

An intense interest in death and dying developed in the early

1960's following the publication of Herman Feifel's collection of essays, The Meaning of Death (Feifel 1959). This marked the beginning of what I will call the "death awareness movement," a popular and scholarly interest in one of the most assiduously avoided topics in our culture. Most interest in death centered on the patient and family in relation to the institutions where they received care or in the psychological process of dying and grief. In particular, the work of Elizabeth Kubler-Ross (1969) addressed the psychological aspects of death for the individual, popularizing such concepts as the "good death" and "normal" responses in dying, such as denial, anger, or bargaining. Interest in hospice care and the importation of Dr. Cecily Saunder's work at St. Christopher's in England followed on the heels of this scholarship. Questions of openness with patients about their poor prognosis, definitions of death, and dignified treatment of the dying were discussed with frequency as new journals and professional societies developed to codify the extensive scholarly interest in thanatology.

The impact of work with dying patients on the professional care giver, however, received considerably less attention. Even worse, in the thanatology literature, care givers were frequently ascribed a villainous role as they carried out the institutional expressions of our general societal response to death. It is doctors, nurses, and social workers, after all, who may fail to inform patients adequately, avoid going into their rooms, or disregard the

psychological needs of the dying and their families. Moreover, they represent the human face behind medical interventions which failed to heal.

Most of the literature which does focus on problems of health providers in this difficult area emphasizes the attitudes of care givers and the stresses experienced by health professionals in providing terminal care. An extensive socio-structural literature on death and dying describes the place of health care institutions in the care of the dying which, in turn, determines the role of the health worker as a care provider.

The literature review provided here serves as a backdrop for this study of health professionals' responses to work with terminally ill patients. While the existing literature in this field may illuminate and refer to concepts used in this study, few studies have actually described the experience from the professional's perspective. To capture this perspective, one must recognize that the health worker is caught between the patient and the family's disappointment with the management of the dying person and the limits of most hospital facilities to deal effectively with their "failures."

This review begins with an overview of the early socio-structural literature on death and dying and continues with research on attitudes of health professionals and the literature on stress and terminal care-giving. A final section reviews writings

on the impact of the Acquired Immune Deficiency Syndrome (AIDS) on medical personnel.

Structural Perspectives on Death and Dying

The socio-structural study of death and dying stresses the interrelationships among complex organizations, health care providers, and dying patients and their families. Applying the sociological lens to the dying patient in the context of contemporary medical care reveals considerable disjuncture between the goals and input requirements of modern hospitals and patients' needs as they approach death. When curative measures are no longer efficacious, health professionals must face uncertainty, failure, and work structures which do not allow for the needs of the dying.

Several classical empirical studies by sociologists date from the 1960's. These works articulate three themes which are the basis of the sociological literature in thanatology -- the lack of congruity between the organizational structure of hospital care and the needs of dying patients, the issue of informing patients about a terminal prognosis, and the impact of sophisticated developments in medical treatment which have prolonged and complicated the dying process. It is important to note from the outset that the death awareness movement has been a social force over the past three decades and has itself changed the context of care for patients,

health professionals, and medical institutions. The interaction of this trend with important technical medical advances has substantially changed the care of the dying. As articulated from the perspective of professional care givers, the study reported here identifies areas of constructive impact, as well as residual problems in the care of dying people in hospitals.

Hospital Structure and the Needs of the Dying

Based on his study of two general hospitals, one private and one public, Sudnow (1967) differentiated death as a biological event from death as a social event. Patients become candidates for social death at the point in their illness when doctors give up hope for recovery, or it appears to staff that they will not improve. When the institution accepts the impending death, it loses interest in the person as a human being and begins to treat patients as if they were already dead. In this way, when the hospital deals with death it can define the facts of death in terms of its own needs rather than those of the patient or his family. For example, Sudnow reported the medical and nursing staff's practice of encouraging family members to go home near the time of the death event. He attributed this practice, at least in part, to the fact that the presence of family members complicated the work of staff who would have to respond to the needs of grieving

relatives. Added to their ordinary ward responsibilities would be the need to demonstrate continuing concern for the benefit of family members who might be present (Sudnow 1967).

Sudnow also documented how house officers in teaching hospitals differentially allocated their attention to patients, concentrating their energies on the more interesting cases in spite of a stated philosophy that full curative attention be given to all patients in their care. From Sudnow's perspective, a change from curative to palliative care had the potential to abdicate medical care completely. He also noted that physicians walked a "medical tightrope" between potentially unfounded optimism about a dying patient and premature pessimism about the prognosis. Doctors therefore maintained an attitude of uncertainty in order to protect themselves from the costs of failure (Sudnow 1967). Quint later echoed the uses of the uncertainty surrounding death as a means of maintaining the doctor's control over the terminal event (Quint 1972).

More recently, Mauksch (1975) looked at the relationship between hospital organization and terminal care. He described the evolution of hospitals from places for the poor, indigent, and dying to their present roles in supporting healing services. The growth of science and technology in medicine affected the culture and ambiance of hospitals. As social organizations, they shifted from places for people to die to institutions for restoring people

to health (Mauksch 1975).

The current roles of health professions are colored by a technical emphasis on healing, which leads to the perception of death as failure. According to Mauksch, "the organizational context of dying within the hospital must be understood as an institutional response to an event which today is identified as failure, although it also remains a reminder of the limitations of medical knowledge and capabilities" (Mauksch 1975, 8). From this perspective, Mauksch confirms the guilt and discomfort of nurses and doctors when they face people entrusted in their care who die in spite of their best efforts (Mauksch 1975).

Additionally, hospitals are organized for the care of the about-to-be-cured, not the dying. They must rationalize the emergencies of patients in order to operate efficiently, in spite of the individual needs of patients. They house a network of occupations which, while ideally complementary, are generally isolated from each other. Particularly with the care of the dying, health professionals have inadequate means for communication, leaving patients without coordination of care (Mauksch 1975).

Noyes and Clancey (1983) have conceptualized the lack of normative fit between dying patients and hospitals by proposing the "dying role" as a variation on Parson's concept of the "sick role." Parsons described the "sick role" as a time-limited, medically conferred social role which concluded with the

restoration of health. It carried with it the obligation of desiring to obtain competent help and of getting well. The sick role entitles a person to exemption from normal social role responsibilities (Parsons 1951).

Noyes and Clancey proposed the "dying role" as a time-limited social role conferred by medical authority. While the sick role ends with restored health, the dying role carries with it an unfavorable prognosis. The dying person may relinquish unrealistic hope of recovery, but should retain the will to live. In assuming this role, the dying person is obliged to arrange for the orderly transfer of property and authority. Dying persons should avail themselves of the necessary supports to life and should cooperate with their administration. They must accept a certain curtailment of freedom, while striving to remain as independent as possible, limiting their claim for attention. The rights and exemptions conferred in this role include the freedom to withdraw from active engagement in the social system, the right to be cared for, and the entitlement of continuing respect and status (Noyes and Clancey 1983).

These authors stress expectations about care givers' responsibilities to the dying. When patients assume the dying role, the physician is no longer primarily responsible for care:

> [The patient] is not expected to remain dependent on the doctor, who has already — in the process of diagnosing a fatal illness — transferred him from the sick to the dying role.

> Having done so, the doctor no longer holds a position of primary importance in the person's care, although he may oversee supportive and palliative treatment. Society reserves the doctor's role for the more important restorative function and in so doing, jealously guards against inroads upon the doctor's time and energy (Noyes and Clancey 1983, 38).

Noyes and Clancey suggest that within the contemporary medical system, dying people have been assigned the sick role, resulting in role confusion, because they become the object of vigorous and active treatment. A conspiracy of silence surrounds the dying person, which precludes the patient's assuming the dying role. These authors call for the recognition of a dying role which they feel would provide open communication, as well as a shift in the doctor's obligation to the patient, with a parallel increase in care by supportive personnel (Noyes and Clancey 1983).

These authors present a crude and artificial description of the "dying role." Yet, by calling attention to the fact that patients at the point of terminal diagnosis patients no longer fit into the sick role construct, they provide a useful guide to the disjuncture between the needs of terminal patients and traditional health care structures. For example, when they list the expectation that patients relinquish the physician as primary care giver, they underscore current medical values by suggesting doctors have a more important social function in curing rather than in relieving patient suffering. But they lose sight of the tenacity with which some physicians pursue cure, even with "hopeless cases." Some

patients have also been described as "fighters" in the context of terminal illness, refusing to forego the pursuit of any available intervention (Erle 1982). When dying patients are in hospital, where the mechanisms for technical intervention are such an integral part of the medical arsenal, they may be subject to their questionably effective use. The technology is available and the entire system is geared to curative measures rather than palliation. In addition, the contemporary medical/legal climate may encourage their use in a defensive manner.

From its inception, the literature of the death awareness movement has examined the disparity between institutional goals of modern hospitals, as well as medical professionals, and the effective and humane treatment of dying patients. The hospice movement developed in response to this disparity. The writings of Cecily Saunders, as well as her model of hospice care in England, St. Christopher's, became the focus of a grass roots movement to develop a hospice alternative of care in this country. The impact of this movement on the general care of dying people will be developed later in Chapter Two of this study.

Disclosure of a Terminal Prognosis

The issue of telling patients and family members about a terminal prognosis occupies a significant proportion of the early

sociological literature on terminal illness. One of the earliest and most conceptually developed studies was Strauss and Glaser's Awareness of Dying (1965), which considered the unwillingness of medical personnel to share an unfavorable prognosis with a dying patient. Strauss and Glaser described this behavior as similar to that of laymen and saw the training of doctors and nurses as preparation for the technical management of death, but not for the emotional responses to death. These authors developed three "awareness contexts" that demonstrated the continuum of openness among patient, family, and staff about impending death -- closed awareness, mutual pretext awareness, and open awareness (Strauss and Glaser 1965).

In the closed awareness context, doctors do not tell patients outright about a terminal prognosis, and families tend to guard the secret. The organization of the hospital, with personnel loyalties committed to the physician, helps maintain the pattern of concealment, and patients have no allies to help them uncover impending death. The second category is mutual pretext awareness. Here, either the staff or patient does not want to discuss the coming death, even after adequate clues and openings are extended. Finally, in an open awareness context, pretense breaks down, either suddenly or gradually, and may represent either a temporary or permanent situation. There is, therefore, usually vacillation between the last two categories (Strauss and Glaser 1965).

Once aware they are dying, patients must follow certain rules of conduct. Above all, patients should not bring about their own deaths. In an effort to minimize any interference with the work of hospital personnel, the patient is expected to remain cheerful and composed, stay in contact with the world, cooperate with care givers, and avoid distressing or embarrassing them. Strauss and Glaser point out that patients frequently do not face death in this way, in spite of cultural notions about courageous and decent behavior at death. They may become hysterical, noisy, make excessive demands, or behave in a hostile or reproachful manner (Strauss and Glaser 1965).

By the 1970's, support for disclosing a patient's diagnosis increased. The trend towards more open discussion with the patient was generally attributed to social and cultural changes. Several researchers reported this phenomenon (Carey and Posavac 1978, Novack et al. 1979, Veatch and Tai 1980), so that by the end of the decade, movement away from withholding a poor prognosis was already gaining recognition. Oncologists, more apt to be exposed to terminally ill patients than other doctors, were even more likely to inform patients about their diagnosis. Specialists with a lower exposure to dying patients were less likely to inform patients (Rea, Greenspoon, and Spilka 1976 and Dickerson and Pearson 1979).

Attitudes of Health Professionals About Terminal Care

Avoidance of Terminally Ill Patients by Care Givers

One of the earliest messages of the death awareness movement was the extent to which our society avoids death and the dying. Death is considered a taboo subject, not a topic for ordinary discourse. In spite of our preoccupation with death and violence as presented in popular films and in the media, we are generally not prone to discuss the dying process. In an early study, Kalish (1966) attempted to identify the relative degree to which college students would distance themselves socially from the dying, as compared with other avoidance-producing groups. Based on his results, this author predicted frequent social isolation of the dying, since the white subjects confirmed they would avoid dying persons to about the same extent that they would avoid Blacks or gamblers. Most would not want a dying person as a friend. Kalish points out that the consequence of death-avoidance behaviors for dying patients may be limited help from family and friends and also from professional care givers (Kalish 1966).

Indeed, the unwillingness of medical personnel to talk directly with patients about terminal prognosis has been attributed to a general societal prohibition. Some have suggested that in the realm of interaction with the dying, health workers behave like lay

persons. While doctors and nurses may be trained in the technical management of the dying, they are as untrained in the affective elements of care to the dying as the general populace. Avoidance is not only reflected in an unwillingness to convey the bad news of a medically hopeless situation; it may also be suggested in professionals' limiting their contact with the dying in their care.

An anecdotal essay describes a range of avoidance strategies on the part of all groups of care givers as a means of addressing the painful feelings of association with the dying. Behaviors that are aimed at distancing the fatally ill patient from the staff member include avoiding the patient by fleeing to other patients who are more rewarding to work with, distancing behaviors, impersonalization, intellectual defenses, such as rationalizing about the patient's condition, blaming the patient, refusing communication with the patient, and using gallows humor in order to reduce anxiety about death (Crary and Crary 1975).

Physician avoidance of dying patients has been noted frequently since the 1960's (Kastenbaum and Aisenberg 1972, Kubler-Ross 1969 and Livingston and Zimet 1965). Considerable speculation as to why doctors avoid death has developed parallel to investigation of the personality structure of physicians or the training and socialization of young doctors. Doctors are described as having a greater fear of their own death than other professionals. Kasper (1959), among others, has described the pursuit of medicine as a

part of the individual's motivation to cure himself and live forever by gaining mastery over life through his profession and in part by objectifying human life. Additionally, the training of a physician emphasizes the capacity to be victorious over death, and doctors use avoidance to mute their disappointment when patients cannot be cured (Kasper 1959).

Paralleling studies which indicate more openness in disclosing a terminal prognosis, a recent study of the interactions between oncology patients and their physicians suggests that avoidance behaviors on the part of physicians attending the dying may be exaggerated or in fact may be changing. Blanchard et al. (1983) observed and quantified patient-physician interactions during morning rounds. Contrary to what these researchers describe as the "prevailing myth," the oncologists in their study in fact spent more time in the rooms of patients with the poorest prognosis than they did in the rooms of patients with the best prognosis (Blanchard et al. 1983). Clearly, more general investigation of avoidance behavior among physicians needs to be carried out, particularly in light of the impact of the past thirty years of death awareness on the attitudes of physicians. Also, new treatments for cancer patients in the past generation have prolonged the lives of many and have extended the relationship with patients for oncologists. This dimension may mean that doctors develop personal relationships with patients over time,

particularly patients with whom they have reaped past successes.

In the sparse literature on nursing attitudes towards the terminally ill, the question of patient avoidance is central. In a study by Pearlman, Stotsky, and Bernard (1969), in which sixty-eight nurses from a range of health care institutions were interviewed, older and more experienced nurses reported being more likely to avoid dying patients. They also felt more uneasy discussing death directly with patients than did younger, less experienced nurses. LeShan (in Kastenbaum and Aisenberg, 1972) clocked the length of time it took nurses to answer bedside calls and found it took significantly longer for nurses to answer calls by terminally ill patients. Kastenbaum (1967) reported that nurses are most likely to avoid discussion of death when patients make direct statements about death. Fatalism, denial, or changing the subject were the most popular responses given by the two hundred nurses and attendants queried. The vast majority evaded any discussion about the patients' thoughts or feelings (Kastenbaum 1967).

Quint (1966) also described the ways in which nurses working in a cancer ward avoided discussions about death. She found that nurses developed composure strategies in work situations which threatened their professional demeanor. Nurses can lose composure on several bases. The nurse can become emotionally attached to a patient, she can find herself negligent, or she can be unable to

perform her job in a manner which she finds professionally acceptable. If a nurse knows that a patient is unlikely to recover, she will use avoidance strategies, such as controlling time spent with the patient or limiting conversation. The nurse may also call in a "death talker," a nurse on staff or other professional person with whom the patient can talk. When nurses feel unable to effectively manage the symptoms of the terminally ill, they will avoid contact with the patient so that they do not have to confront their sense of personal inadequacy. Additionally, nurses will avoid expressive behavior around seriously ill patients to protect themselves from feelings of personal involvement (Quint 1966).

Attitudes towards Withholding Treatment or Prolonging Life

Besides medical personnel avoidance of dying patients, their attitudes towards withholding medical treatment or prolonging life for patients near death have also been studied. Greer and Mor (1984) observed that researchers have noted evolution in these attitudes over time, again influenced by social and cultural factors. For example, Carey and Posavac (1978) refer to the Karen Anne Quinlan case as one event which pressured the American medical community to develop guidelines for determining what life-sustaining practices are appropriate in terminal care.

In the 1970's two studies conducted five years apart used the same questionnaire distributed to similar populations (Travis et al. 1974 and Noyes et al. 1977). Among the medical students, house staff, and clinical faculty surveyed, a 13 to 23% increase in support for withholding treatment from the terminally ill was noted between the earlier and the later study. The greatest increase in support of withholding treatment over the five year period was seen among the interns and residents.

Withholding medical treatment, or passive euthanasia, is distinguished from active euthanasia. In a comparative study of attitudes of doctors, nurses, hospital chaplains, and non-hospital college students, all groups strongly supported not using extraordinary measures to sustain a terminally ill patient's life. The respondents were more ambivalent as to whether or not "quality of life" criteria should replace other criteria in decisions on withholding treatment. While a majority of the college students and student doctors supported active euthanasia, only 20% of doctors, nurses, and hospital chaplains endorsed "mercy killing" (Carey and Posavac 1978). In their study of nurses and terminally ill patients, Hoggatt and Spilka (1978) reported overwhelming opposition among nurses to the use of extreme measures to support life when there was reason to believe such efforts would be futile: 90% of the nurses in their study opposed extreme life-supporting measures, as compared to 63% of physicians studied in the same

period, a finding the authors attribute to nurses' more intimate contact with patients. The question of medical controversy about do-not-resuscitate orders, a specific technology used to prolong life, will be discussed in Chapter Two.

Health Professional Stress in Terminal Care

Providing care to dying patients can have a negative impact on the emotional well-being of professional care givers. The stress associated with this work has been a topic of interest to researchers since the 1970's, particularly in relation to nurses, who have the most unremitting contact with dying patients (Mor et al. 1984 and Grey-Toft and Anderson 1985). For example, nurses working in coronary care units experience unique stress because of their repeated contact with death (Hay and Oken 1972). The work has been described as a process of forming releationships and at the same time preparing for their termination (Price and Bergen 1977).

The process of repeated development and loss of intimate relationships is also apparent in hospice care, and in fact, much of the literature on stress and burnout for care givers to the terminally ill developed in relation to hospice care (Yancik 1984 and Vachon 1983), where the philosophy of care included supportive interventions for staff and a recognition of the stressful

consequences of sharing the grief process in an intimate way with patients and their families. The high idealism of the hospice philosophy of care in comparison with the realities of terminal care when health care personnel cannot adequately respond to patient need may place unrealistically high expectations on staff, adding to their stress (Vauchon et al. 1978).

Many other factors are noted to create stress for care givers to the dying, such as having to deal with patient's verbalizations about their fears of death. Particularly when patients have high social value when dying patients are young or where there are consequences for young children, staff may experience profound stress in doing their work. The probability that some care givers may blur the boundaries between being responsible for the care of the patient with being responsible for the patient's illness or death may be yet another source of stress (Beszterczey 1977), woven into the present medical context where our technological successes have been so profound.

Three major stress-provoking areas in hospice work were identified by Yanick -- staff support, emotional concern for patients and families, and management of disease. Lack of staff support was the greatest overall producer of stress among the hospice care givers studied (Yanick 1984). Other researchers also report that problems with the work situation and staff communication appear to be at least equally contributive to staff

stress as does having to watch patients suffer and die (Vachon et al. 1978).

As defined by Pines and Maslach, "burnout" is "a syndrome of physical and emotional exhaustion, involving development of negative self-concept, negative job attitudes, and a loss of concern and feeling for clients" (Pines and Maslach, 1978, 48). Burnout can result in the professionals distancing themselves so they can continue to work without being overwhelmed. The cumulative effects of stressful work can result not only in emotional withdrawal from the work, but physical withdrawal as well. The problem of staff turnover in such circumstances creates serious institutional problems and problems in continuity of care for patients.

Numerous studies have been carried out in an effort to understand the causes and manifestations of burnout in work with the terminally ill. Many of these studies look for variables which are attributes of the health workers themselves as predictive of high levels of stress and burnout. The youth of the staff member and higher levels of education are consistently associated with a tendency towards burnout, probably because of the idealism and high levels of motivation among young, well educated staff who are ill prepared for the reality of limited patient improvement (Masterson-Allen et al. 1985, Mor and Laliberte 1984).

Apart from personal variables, work-related factors can also be predictors of burnout. Long tenure and full-time status are associated with burnout, suggesting that shortened work time or respite is an important supportive element in terminal care (Chiriboga et al. 1983, Masterson-Allen et al. 1985 and Mor et al. 1984).

Health Workers and AIDS: Review of the Literature

Background

The acquired immune deficiency syndrome (AIDS) is a rapidly progressive and currently terminal disease. AIDS was first reported in the United States in 1981. AIDS is the most serious disease to result from infection with a human retrovirus known as human immunodeficiency virus (HIV). With HIV infection, a patient can be asymptomatic for years before the first manifestations of illness appear. But as the HIV virus attacks the immune system, previously healthy people become vulnerable to otherwise manageable medical problems such as weight loss and diarrhea, and ultimately to rare infections and cancers such as pneumocystis carinii pneumonia (PCP) and Kaposi's sarcoma.

AIDS was originally identified in the United States among homosexual and bisexual men, and shortly after, among IV drug users. The vast majority of cases now reported still come from these two population groups. Other cases have been reported in blood recipients, hemophiliacs, female sexual partners of infected men, and children born to mothers infected with HIV.

Health workers in the major teaching hospitals in coastal cities in the United States have borne the burden of direct care for hospitalized AIDS patients. Because of the sudden and concentrated appearance of the illness doctors, nurses, and social workers were ill-prepared to care for the large numbers of terminally ill young, people for the most part from stigmatized groups, who sought treatment in hospitals. During the early years of the epidemic health professionals had little choice in this aspect of their work (Volberding and Abrams 1985). For example, interns and residents caring for persons with AIDS early in the epidemic had accepted training in prestigious medical centers before the first cases were identified. Certainly no one could have anticipated the profound impact AIDS would have on the cohorts in training after 1982 (Wachter 1986).

The HIV virus is spread through blood and sexual contact; there has been little spread beyond the initial risk groups. Yet reports by the Centers for Disease Control (CDC) about three health workers

who seroconverted, or tested positive for HIV infection, after caring for AIDS patients (Centers for Disease Control 1987) underscored anxiety on the part of health professionals about HIV infection.

Work-related transmission of the HIV virus has been documented in a minuscule number of accidents. Nevertheless, in the context of uncertain knowledge and media hysteria, health workers worry about exposure in the course of their work. Workers grapple with fears of contagion of a disease which so far is invariably fatal. While there is no doubt that the major psychosocial victims of this disease are the AIDS patients themselves, health professionals clearly experience its psychological impact. The impact of AIDS on the health system generally, will be discussed in Chapter Two. Following is a review of the literature on health workers and AIDS.

Problems in Social and Psychological Investigations of AIDS

Since the first AIDS cases were reported in 1981, the disease has captured the attention of a group of eminent and dedicated biomedical scientists and epidemiologists. In a very short time this elite cadre of investigators has learned a great deal about the disease. While sometimes criticized for excessive competitiveness or for exploiting the relative unavailability of research funds for AIDS, they have advanced our understanding of

the epidemiology and immunology of the illness, developed the means to identify the causal virus and protect the blood supply from contamination, and have run and reviewed clinical trials on many possible drug treatments, including the identification of successful treatment with Zidovudine (AZT) for HIV infected and AIDS patients .

Investigations of the psychosocial aspects of AIDS have been hampered by misunderstanding about the two communities most affected by AIDS -- gay men and IV drug abusers. Biomedical, epidemiological, and psychosocial researchers experienced major problems in studying these two groups. For IV drug abusers, the problems of identification, follow-up, and controls are almost insurmountable and have led to the exclusion of IV drug abusers from certain studies. For example, anyone with a history of IV drug abusers was excluded from the clinical trials of AZT because of anticipated problems with compliance and reliability (Laskin, personal interview 1987).

In studies of homosexual men, the pervasive heterosexual ignorance of Gay life-styles and sexual activities have led to questionable study designs and instruments which do not account for actual sexual practices. According to Batchelor, "The indelicacy of discussing intimate sexual practices, especially unfamiliar ones, has resulted in scientific terminology and careful euphemisms in survey instruments that confuse the participant more than they

add precision to data collection" (Batchelor 1984, 1282). Untangling the political meaning of recent male homosexual practices in a bewildering process for heterosexuals. Political perspectives, often strident expressions of Gay rights issues, have infused some of the best efforts at understanding the psychodynamics of this illness. Dennis Altman who has written extensively on homosexuals, says, "During the 1970's the growth of both Gay assertion and a commercial Gay world meant an affirmation of sex outside relationships as a positive good, a means of expressing both sensuality and community" (Altman 1986, 142).

This review focuses on one specific aspect of the psychosocial literature on AIDS, the disease's impact on health professionals. When health professionals are presented in the AIDS literature, it is often in relation to patient abandonment (Nelson, Maxey, and Keith 1984), refusal to treat patients (Plumeri, 1984), or fears of contagion. These issues are discussed from a moral perspective (Kayal 1985 and Loewy 1986) or to review safety practices in the hospital (Bennett 1986). The responses of health workers to stigmatized social groups has been discussed (Douglas, Kalman, and Kalman 1985 and Forstein 1984), but the impact of the illness on work lives of caregivers is only mentioned in passing (Holland and Tross 1985 and Nichols 1984). A number of articles reporting surveys of physicians' attitudes towards AIDS patients and their knowledge about the disease have appeared (Richarson et al. 1987

and Kelley et al. 1987). This reflects concern that doctors are reluctant to serve AIDS patients, as well as the recognition that manpower as well as financial resources are critical in responding to this disease.

Most of the literature on health workers and AIDS has developed in response to the widespread reports of fears and concerns generated in this work community about the contagion of AIDS. A second body of literature examines the psychological costs for health professionals who work with AIDS patients. These two issues will be discussed in the next two sections.

The Fear of Contagion: Viral and Social Contamination

When health professionals have been referred to in the AIDS literature, it has generally been in relation to their fears of contracting this fatal disease. The lay press and the professional literature both report health workers' refusal to care for patients or excessive precautions, such as trays left outside patients' doors, nurses' refusal to bathe patients, or unnecessary gowning by personnel entering AIDS patients' rooms (Weiss 1983). Although most of these patient-rejecting behaviors were reported very early, in March, 1987, a prominent heart surgeon in Wisconsin refused to operate on patients infected with the HIV virus (The New York Times March 13, 1987). Also, in September, 1987, cardio-pulmonary

surgeons in a large private medical center in New York refused to perform valve replacement procedures on known IV drug abusers because of the high incidence of HIV infection in that population (Aras, Personal Communication 1987). Reports such as these have led to accusations that health workers have abandoned AIDS patients, culminating in a public condemnation of such behavior by physicians by Surgeon General C. Everett Koop (Boffey 1987).

The extremity of avoidance suggests that health workers' fears originate to some extent in concerns about the possible social as well as physical contamination from work with stigmatized populations. In fact, some writers have described the AIDS diagnosis as a social as well as a medical classification (Ostrow 1984). The selectivity of this disease, at least in its initial appearance, for socially stigmatized groups has borne with it the attribution of causality by these groups (Fox 1986 and Kayal 1985). Workers not only fear viral transmission but also social contagion or perhaps the social stigma of these groups intensifies the fear of physical contagion. Holland and Tross (1985) from Memorial Sloan-Kettering Cancer Center, recognized that interaction with stigmatized groups such as homosexuals or IV drug abusers goes far to unmask the negative attitudes of health professionals, which are similar to those of lay people. Negative responses which may otherwise have laid dormant can intrude on the relationship between

patient and caregiver. They can seriously affect the ability to provide emotional support and understanding, and preclude open discussion of sexual preferences and practices.

Contamination is a psychological issue as well. Stuart E. Nichols, who has studied the psychological impact of AIDS since 1981, describes the problem in psychodynamic terms: "When panic is experienced by persons not at risk, it might be derived from the old fear of exposure -- the fear of discovering homosexual feeling, not of contact with the putative AIDS agent" (Nichols 1985, 90). From whatever source, biomedical, social, or psychological, AIDS anxiety within the medical and nursing communities has generated a large segment of writings about health workers and AIDS.

A number of articles have appeared in nursing and medical journals describing protection against the risk of disease transmission for workers in health settings (_Hospitals_ 1984, Bennett 1986, and Conte et al. 1983). Typically, these articles review essential protocols for caring for AIDS patients. The authors often refer to "panic" or "hysteria" to describe health workers' reactions to contact with this group of patients, words which reflect the intensity of these concerns among professionals. An article from the "Management Rounds" section of _Hospitals_ explicitly states that the "key to demystifying the disease is educating the staff about what precautions to take when caring for

AIDS patients" (Hospitals 1984, 40). All these articles imply that the dissemination of scientific information will provide a basis for rational action by health workers and will neutralize the hysterical responses to non-scientific sources, such as the media or rumors. Thus, these articles provide such information in clear terms related to specific professional activities required for direct patient care.

One response to reports of hospital-worker "abandonment" of AIDS patients is to admonish them to serve as professionals on moral grounds. An article in RN entitled "Are we abandoning the AIDS patient?" proposes that nursing is not only a profession, it is also a vocation: "It's a calling to serve -- an inner voice that urges us to work for a better world. As nurses, our call to care for the sick and dying supersedes fear of disease" (Nelson et al. 1984, 18). These nurse authors ask their colleagues if they have lost the courage to serve and plead for compassionate care for AIDS patients. Finegold, a physician, evokes Osler, Hippocrates, and Lewis Thomas to encourage physicians to assume their responsibility to AIDS patients (Feingold 1983).

Although he uses historical scholarship, Loewy (1985) responds to the problem of health-workers' fears of AIDS with an appeal to professional values. Troubled by reports of physicians refusing to care for AIDS patients and an ambivalent community response to those refusals, Lowey examined the concepts of "duty," "fear," and

"courage" in a medical setting. He argues that an enduring social contract binds the healer to the community. He reviewed the historical obligation of physicians to treat their patients despite personal risks by describing physician's actions during plagues during from the Justinian Plague, which lasted from c. 540-590. Historically, the doctors' social contract required that they remain with the diseased population. The status, prestige, and power of physicians meant that they were obliged to serve good patients as well as bad. Lowey feels that the present post-antibiotic generation of physicians may have been spoiled by not having to fear exposure to infectious disease (Loewy 1985). Others are more sympathetic to doctors of the present generation citing the fact that the causative agent of AIDS was originally unknown exacerbated uncertainty in an unfamiliar context (Volberding and Abrams 1985).

Others have defined the legal obligation to serve AIDS patients. Plumeri, an attorney writing in the Journal of Clinical Gastroenterology, proposed a hypothetical example of a gastroenterologist refusing to perform an endoscopy on an AIDS patient because of fear of exposure to the patient's virus laden bodily secretions. Although a physician has no legal duty to treat a patient, once a relationship arises from a consensual transaction or an expressed or implied contract, s/he does have such a legal duty. Plumeri clearly outlines the circumstances under which a

doctor has a legal obligation to treat, providing as well rationale for avoidance for physicians concerned about treating AIDS patients. The author seems to imply that the anxiety doctors experience in the matter of treating AIDS patients may also include a fear of lawsuits (Plumeri 1984).

In 1984, Valenti and Anarella surveyed hospital personnel at their own institution, Strong Memorial Hospital, on their understanding of AIDS. This survey was one of the first reported which directly addressed the knowledge and attitudes of health personnel working in a teaching-hospital setting, and remains one of the few to compare the responses of various hospital disciplines. Seven hundred forty-one questionnaires were distributed among hospital employees likely to have contact with AIDS patients. A 36% response rate of 266 completed surveys yielded data from thirteen employee groupings. Although understanding of AIDS and its transmission increased with the educational level of the respondents, certain aspects of AIDS transmission still raised anxiety, even among doctors and nurses. As an example, the authors noted the fact that while most employees knew that the virus was not airborne and that casual contact does not pose a threat of transmission, there appeared to be uncertainty about the need for masks and gowns in routine situations, or whether common waiting rooms were acceptable (Valenti and Anarella 1986).

Findings from this study raise question as to whether education limited to safe practices alone will adequately inform professional activity with AIDS patients. The authors draw a parallel between the disparity in areas of knowledge and action in hospital personnel and the general public's generally high level of knowledge, which does not always inform community action. For example, the protests against children with AIDS entering public school in Queens, New York, took place in the context of high levels of awareness about AIDS in that community. The authors state that for their respondents, the media was the major source of information about AIDS. They speculated that some media coverage might directly conflict with what was taught in in-service training programs, resulting in confusion over the actual modes of transmission of AIDS. These authors conclude that "those responsible for educating hospital staff are faced with a dilemma that may not easily be surmounted by the traditional educational approach alone. Additional counseling to help employees overcome their own stress and anxiety might also be indicated in some situations. Other religious and social beliefs may further complicate the issues" (Valenti and Anarella 1986, 62-63).

The interplay of fears of the AIDS virus with homophobic responses of professional workers as well as in the wider community has become almost a cliche in the AIDS literature. Another survey of doctors and nurses in a large urban teaching hospital tried to

quantify the degree of homophobia in this population by using an existing instrument designed to measure homophobia. The authors distributed the test to 91 house officers and 261 registered nurses. The response rates were low; in this voluntary and anonymous study, only 41 percent of the physicians and 35 percent of the nurses responded. The authors were alarmed to find that the mean scores of respondents fell in the homophobic, though low-grade, range and that 10 percent of their respondents agreed with the statement that AIDS patients got what they deserved. Predictably, the authors note lower homophobia scores in nurses and doctors who personally knew a homosexual or had a homosexual family member (Douglas et al. 1985).

It is likely that homophobic responses are more pervasive, since the survey methodology used for this study may have helped to protect some of the more negative responses behind the workers' professional veneer. The low response might also suggest a fairly high incidence of homophobia in this community. Low response rates are found in other studies of health workers' attitudes towards AIDS: an average 36 percent response rate among 13 hospital employee groups (Valenti and Anarella 1986), a 55 percent response rate from physicians with known contact with persons with AIDS in the California Bay Area community (McKusick et al. 1986).

As a result of the appearance, virulence, and spread of AIDS, health workers had to confront many unknowns. In this instance,

the "unknown" included not only a new and dreadful disease but also populations in our society which participate in mysterious, unfamiliar, and in some eyes, sinful practices. Increased information about the disease, along with personal contact with homosexuals and IV drug users stricken with AIDS may decrease health workers' fears, or may solidify their negative responses.

The Psychological Impact of AIDS on Health Workers

Work with AIDS patients generates a complex response among health workers providing direct care. Fears of viral contamination and association with stigmatized social groups conflict with professional expectations for objective medical practice and a social obligation of service. Compounding the difficulty for health professionals is the current fatal prognosis and the young and previously healthy population it attacks.

Writers describing the psychological responses of AIDS caregivers generally refer to helplessness and corresponding anger. Physicians are the professional group most mentioned, although some observations also pertain to other professional groups. Holland and Tross (1985) point out the sense of identification and personal vulnerability in caring for young patients who face rapid deteriorating and death. Wachter, a young physician trained during the early days of the disease, also notes

the youth of the affected patients as a compounding element for doctors-in-training. He remarks that house officers commonly build defenses quickly against their constant exposure to death, using peer support, intellectualization, and gallows humor. But with AIDS, because of the youth of the patients and the doctor's powerlessness to influence disease outcome, the usual defenses are inadequate (Wachter 1986). Several authors refer to physicians' anger in dealing with a disease they cannot cure, which therefore threatens them professionally.

Most of the references to health personnel's psychological responses to AIDS are made in passing in articles on the impact of AIDS on more directly affected populations. Only one study specifically addressed the psychological impact of AIDS on a caregiver population. In this study researchers at the University of California at San Francisco studied psychological reactions and attitudes of primary care physicians working with AIDS patients. They assessed the degree of depression, anxiety, overwork, fear of death, intellectual satisfaction, and career satisfaction through a survey instrument and interview. Eighty-two physicians were surveyed, forty of whom agreed to be interviewed. Predictably, a majority of the informants reported increased stress since they began working with AIDS patients. A significant minority reported increased fear of death and anxiety. Sixty-three percent of the sample identified themselves as "gay-oriented." This group was

more likely to report an increased fear of death and anxiety than their heterosexual counterparts. Through the interview material, the researchers determined that the increased anxiety was due to the "gay-oriented" physician's perception of being at risk himself for AIDS. Psychological distress increased directly with physician contact with AIDS patients, career and intellectual satisfaction also increased similarly (McKusick 1986). Though limited in scope, this study begins to address important issues about the impact of AIDS on professional health workers. Most significant for this reader is its addressing the problem from the perspective of health workers.

Conclusion

In this chapter, I have presented an introduction to the study and a review of the literature on death and dying which has developed over the past thirty years. This review has focused on research on the care of terminally ill patients and the responses of institutions and health professionals to the dying. The review also summarized the developing literature on health professionals and AIDS.

The major knowledge areas presented here included an overview of the early socio-structural literature on terminal care and research on the attitudes of health professions in dealing with

dying patients. Avoidance of the dying and support for withholding treatment were major themes reviewed, as well as the literature on stress in death work and the effects on health professionals. The impact of AIDS patients on health professionals was presented in the final section of the review.

This review serves as an introduction to the major issues developed in the thanatology literature over three decades and indicates the influence and direction of the death awareness movement over this period of time. As presented here, the literature points to changes in the areas of disclosure of a terminal diagnosis, avoidance of dying patients, and questions about the appropriateness of prolonging the lives of patients with terminal disease. It is a backdrop for the study presented here, particularly in relation to assessing how a period of great interest in terminal care affected health professionals who are working with dying patients at present, specifically health professionals who care for the dying in the context of an acute care hospital, where the goal of cure remains the measure of success.

CHAPTER TWO

THE PROJECT SITE: DESCRIPTION OF THE SETTING

Introduction

This study of responses to terminally ill patients by doctors, nurses, and social workers was undertaken in a prestigious urban teaching hospital, which I will call East End Hospital (EEH). The project was conducted during a period of transition for health care in general, as well as for this institution. I began this research in a year where hospitals in this city faced many changes, among them, new systems of a third part reimbursement; new ethical dilemmas associated with advances in resuscitation and other life-sustaining interventions; the growth of new private and group systems of health delivery; and a deadly new disease, AIDS. Three of these issues significantly affected the hospital in relation to terminal care: new regulations for Medicare reimbursement for inpatient services, ethical and legal questions about life-sustaining treatments, and dramatic increase in the numbers of patients suffering from AIDS.

This chapter discusses the organizational structure and culture of East End Hospital and describes how these health care issues

affected the terminal care it provided. The organizational perspective provides the framework for understanding how the care of terminally ill patients and their families produced stress for nurses, doctors, and social workers. More generally, the organization provides a context in which to examine the congruence of institutional and personal goals as hospital workers go about the business of serving the prodigious needs of dying patients. To develop the reader's understanding of the context for patient care, I will describe the hospital-medical complex as well as trends in health care delivery during the period of the study.

The first section focuses on the project site. It includes a general description of the hospital, its organization as a teaching institution, and the culture of this particular medical complex. I describe the organization of the Social Work Department, with particular attention to administrative changes which took place during the study year, and the climate within the Department of Nursing, as nursing administration responded to pressures for fiscal restraints.

The second section of this chapter summarizes selected contemporary issues in health care delivery which bear upon the central theme of the project -- problems which acute care hospitals and health care professionals experience in serving the needs of dying patients. Contemporary trends resulted in many changes for medical, nursing, and social service workers and their

administrators at EEH. The observations and interview material which I collected as a part of this project reflect the efforts of staff to manage their work with these terminally ill patients during a transitional period in health care. In this section I summarize the following issues: the implementation of Medicare reimbursement by Diagnostic Related Groups (DRGs); ethical dilemmas and practical concerns in terminal care, with the advent of the Hospice legislation; and how an increasingly large population of AIDS patients impacted on the hospital.

The final section of this chapter describes my position in the hospital-medical complex. I discuss the unique access my work gave me to the activities of the nurses, doctors, and social workers who were the subjects of this investigation. I also describe the problems of being a social science investigator among biomedical researchers.

The Hospital Medical Complex

General Description

This study of the responses of health professionals to patients in terminal care was undertaken at East End Hospital (EEH), a 1,000-bed voluntary teaching hospital located in a large urban city. The hospital is affiliated with the prestigious Ivy

University Medical College (IUMC) which occupies the adjacent site. EEH is a tertiary care facility with an international reputation. The institution serves both adults and children through a wide variety of ambulatory and in-patient services. As a tertiary care facility, EEH serves patients with complex diseases in advanced stages. Patients are frequently referred by local doctors from the metropolitan area and beyond. The attending physician may therefore not know the patient prior to admission, and the patient may not be a local resident.

In spite of its close proximity to an internationally renowned cancer research complex, Metro Oncology, EEH has an extensive Hematology/Oncology Service. These institutions are to some extent competitive, even though they are both affiliated with IUMC and share some resources. For example, the cancer hospital provided radiation evaluation and therapy services to EEH during the period of this study, while EEH built a new facility. The new EEH radiation therapy unit is supervised and staffed by the Metro Oncology personnel.

The medical complex is an environment of competing constituencies, mirrored in an institutional structure which is organized along the lines of an advisory bureaucracy. Each department is a fiefdom, the domain of the individual chief of service, whose primary concern is autonomy and the enhancement of his or her own territory (Strain 1975). At EEH, this situation

makes for intense competition between departments, each vying for its share of institutional resources and status. In this regard, senior attending staff are more responsive to the approbation or censure of their colleagues than they are to the patients they treat.

Medical Training Program

IUMC graduates 100 students from its M.D. program each year. Places in the program are considered desirable, since IUMC is an Ivy League medical school. IUMC trains house officers in medicine, surgery, pediatrics, obstetrics, and psychiatry through a traditional intern rotation and residency program. Training at IUMC has historically been prized by medical school graduates as a prestigious institution. As with the hospital, competition among departments in the medical college shapes the activities of the department heads. Since the National Institutes of Health (NIH) provides support for the college through biomedical research grants, department heads must enhance their financial resources through government grants. These efforts are a primary focus of the faculty, which places less emphasis on the inculcation of professional practice values among younger physicians in training.

In essence, teaching hospitals with medical school affiliations, such as EEH, have three goals. They strive to offer

optimal clinical services to patients, provide clinical training in a variety of medical specialties and sub-specialties, and foster medical research. The practices and operational framework of such institutions have evolved in order to implement these goals. Nevertheless, these three goals are frequently in conflict (Strain 1975). Understanding the sources of these conflicts is a salient theme of this study, particularly where conflicting goals undermine patient care, which the general community presumes is an important objective of the hospital.

Organization of Care in the Teaching Hospital

At EEH, patients are divided into private and "pavilion" groups. These two patient groups are generally housed in different areas of the hospital, with different structures for care. Private patients are treated by their own physicians, with the tacit understanding that the patient will provide a teaching experience for the house staff -- the interns and residents who are doctors-in-training who are responsible for the coverage of patients "in house." It is also understood that house staff will provide "body care" for the private patient, but that collaboration in formulating a treatment plan is off limits. For private patients, the treatment plan is developed by the attending and consultant specialists. Even though only house officers are able

to write patient orders under the "closed book" system, attending physicians control the care of their private patients.

Pavilion or ward patients at EEH are not covered by private third party reimbursement plans or Medicare. They are admitted through a "comp-care" physician, an attending physician who is a faculty member of the medical college. Unlike the private patient, the ward patient is unknown to the attending before admission to the hospital. While the care of pavilion patients is supervised by the "comp-care" attending, the house staff has considerable autonomy over the treatment plan for these patients. It is through practice with the ward patients that interns and residents exercise the most self-direction in treating patients. The "comp-care" attendings are respectful of the house staff's need to develop autonomy in their practice and generally leave decision making to the interns and residents.

House officers rotate throughout the private and pavilion services at the hospital. In this way they can work with the widest possible range of disease and patient types in their training. For interns, the rotations usually last one month on a given service. At the end of this time, the patient is transferred to the next group of interns who assume responsibility for the service. The formal vehicle for transmitting information about the patient to the new intern is the "off-service" note. Given the rotation system, continuity of care is impossible for pavilion

patients and, to some extent, difficult for private patients. For while the private patient will always have the same complement of attending physicians, the house officer is, nonetheless, the most immediate source of daily care. Besides the rotation of physicians-in-training it should be noted here that nurses also rotate, in the sense that while they generally remain on the same ward, they move from patient to patient on a daily basis. The rationale for this procedure is that it protects an individual nurse from having a concentration of difficult patients.

The intern year is considered the most difficult training year for house staff. Besides the pressure of rotations, interns have the lowest position in the house staff hierarchy. While third and fourth year medical students function as "sub-interns," they are protected from these pressures because of their student status. Interns have the most "scut" work or undesirable tasks to perform. They also have the least knowledge both of the hospital system and therapeutics, which adds to the pressure of their work.

The prestige of the affiliated teaching hospital rests on the academic and research standing of its chiefs of service and medical college faculty. In-house medical care is structured to accommodate the training needs of the house staff (Strain 1975). Obviously, continuity of care would maximize the possibility for establishing relationships with patients, and social and psychological dimensions of the patients' illnesses could be more

pointedly addressed. For house staff, learning about diagnosis and therapeutics is the focus of their work. It is the area most rewarded by their peers and their immediate medical supervisors.

In a study of the socialization of house staff, Mizrahi (1986) describes how they soon discover what is important to the doctors higher up in the medical hierarchy, and they are quick to conform to these standards. The institution, the department heads, and those in charge of house staff training focus on the technical and research aspects of their work, and it is in this area of their work that the novice physician achieves status. As Strain (1975) points out, excellence in patient care and treatment is less likely to be a priority. It is scrutinized by the much more diffuse eye of the general community, but does not convey equal status within medical institutions, where it is considered a basis for standard medical competence.

Organizational Culture

EEH was chartered before the Revolutionary War by the King of England. Hospital staff humorously refer to this historical fact to express their perception that the institution is resistant to change. Compared with other similar hospitals in the metropolitan area, EEH is traditional and conservative. As an example of its conservatism, EEH is exceptionally sensitive to the differential

status among hospital workers. In this regard, the hospital pays complete homage to the physician. The trappings of status dramatically distinguish the superior value of physicians as compared with the "paraprofessional staff," Freidson's term for health professionals such as nurses and social workers who work around the doctors, and whose function is to support the doctors' work (Freidson 1970).

Evidence of the prized value of the doctor is manifest throughout the facility. The hospital maintains a well-staffed doctors' coat room, where attending physicians find freshly laundered coats each day. Here they have access to a dignified, wood-panelled lounge, complete with leather furniture and daily newspapers. The in-house telephone directory is color-coded and divided into sections according to the status of the employee in the hospital. This format is complex and difficult to use since the user must first identify the correct section before finding the worker's name. Yet the system supports the separation of hospital personnel according to their perceived institutional value. Convenience of use appears to be of less value than organizing personnel according to their status. Normative behavior for EEH house officers is conveyed to each new cohort of interns, who are expected to conform to "gentlemanly" codes of dress and decorum when engaged in collegial and patient interaction.

Unlike virtually all other major hospitals in the area,

EEH-IUMC is entirely non-unionized. This striking fact illustrates the paternalistic quality of the medically dominant authority structure. The hospital has managed to control efforts at unionization with pay scales and benefit packages which are exceptionally competitive with comparable institutions in the same city. Other perquisites of employment at EEH-IUMC have made it possible for the administration to resist unionization while at the same time retaining the loyalty of non-medical staff. These rewards enhance the ability of the institution to attract personnel who will happily tolerate the lack of union protection in exchange for a comfortable work setting. The Hospital and Medical College are located in an excellent neighborhood. For staff who live in hospital subsidized housing, residence in this area at inexpensive rents is a significant reward, particularly when compared to the locales of other excellent teaching hospitals in the city.

EEH has traditionally served the health needs of an affluent and celebrated patient population. For workers, one attraction of the institution is the large proportion of upper middle class patients, as well as a significant number of famous patients. The fact that many national and international celebrities seek care at this hospital contributes to an aura of elitism and an organizational culture which stresses dignity, discretion, and decorum. These qualities may appeal to professional and paraprofessional staff alike, who value the conferred status of

association with high-status patients.

The sister institutions of EEH and IUMC are exceptional in their ability to attract benefactors. An aggressive Development Office carries out numerous seminars and open-house days to garner support from its affluent neighborhood. Programs such as "Women and Health Day" or the Departmental Associates provide community service in health education to wealthy contributors from the neighborhood in exchange for financial support. The hospital encourages media exposure of its affiliated attendings. Among the glossy publications generated by the Public Affairs Office is a review of newspaper and magazine articles which contain the work of EEH physicians.

As an institution, EEH has focused its reputation on excellence in patient care for the affluent, and scientific and technical advancement. This has earned the hospital prominence in the city's powerful economic and social communities. To a much lesser extent, EEH has exploited its potential for social or community action. While other large medical complexes in the metropolitan area have clinical and research programs targeted at needy populations in their midst, EEH-IUMC has limited community service programs. A striking example is the Department of Gerontology, which has no clinical or service component. That department limits itself to basic science research in the area of aging. Typically, grants sought by the Medical College have been for basic science or

clinical research. Only within the past year has EEH-IUMC began to look at grant opportunities in social health stimulated by the efforts of a new Social Service Director.

The Social Service Department

General Description

The Social Work Department at East End Hospital was established in 1911. In keeping with the prevailing culture of the hospital, the department has historically been a conservative one, that is, it has for the most part limited its tasks to needs defined by physicians perceptions' of social service functions. From informal comments by attendings and house officers it is clear that EEH physicians see this function as limited to discharge planning. Statements by these medical personnel such as, "they are here for garbage removal," or "they keep the drains open" project this attitude. Also, medical personnel tend to see this function as clerical and concrete.

In a city where social work departments have been marked by progressive reorganization efforts within their parent institutions as well as in the community, this department has conformed to the prevailing physician-dominant perspective of the institution. Historically, the department administration did little to assert

the values of the social work profession when they have conflicted with medical authority.

During the period of this study, 37 social workers staffed the department, 35 of whom held M.S.W. degrees. Two were completing doctoral degrees in Social Welfare. When judged by the educational achievements of its workers, the staff was highly professionalized. There was minimal minority representation in the staff. Three workers were Hispanic and four Black. The department has a student training program; it has long-term relationships with two prestigious schools of social work. During the academic year in which this study was implemented, five M.S.W. candidates were placed as interns in the department.

As indicated earlier, EEH is not a unionized institution, yet the salary range and benefit package for departmental personnel are competitive with similar hospitals in the area. The starting salary for social workers with M.S.W. degrees during the year of the study was $24,424. As described earlier, in relation to staff in general social workers consider EEH a prestigious institution in which to work. The excellent location of the hospital and the association with an upper middle class patient population appeal to staff.

Unlike the elaborate facilities available to the attending medical staff, social workers occupy offices of limited size and convenience for their actual work assignments. Social work offices

are spread throughout the hospital plant. They are frequently located a considerable distance from the service where staff members work. The offices are generally small, windowless rooms. In some instances they have been converted from closets or slop rooms. Since their offices are inhospitable and/or inconvenient, social workers have difficulty seeing family members alone, let alone in groups, in a private office setting. Some offices are far from the worker's service, making them less visible to patients and less integrated into the life of their units. Because the physical plant at EEH is large and the elevators slow, off-service offices make it difficult for workers to accomplish their tasks.

The New Social Service Administration

In December, 1983, the Director of Social Service announced her retirement. Like many in the social work staff, the director had long experience at EEH, including 21 years as head of the social service department. Her predecessor had assumed this position for an equally long time. On March 1, 1984, her retirement went into effect. For six months, the department was administered by the Assistant Director. The new director was announced in the summer of 1984. The Director-designate had previously been the Assistant Director at Metro Oncology and Director of Social Service in a specialized hospital in the same city for several years. She began

her employment as Director of Social Service in September, 1984.

The reaction of both the outgoing administration and the social work staff to the appointment was highly enthusiastic. The new Director had been the favorite candidate of the retired Director. Many departmental workers knew the candidate personally or by reputation before she arrived at the institution. Workers reported informally that they anticipated she would help the department by being a strong advocate for social work within the hospital. She was perceived as less likely than her predecessor to give in to the demands of the hospital administration and more likely to be equitable in her dealings with the social work staff. She was seen as interested in the professional development of the department and in worker education. Some workers articulated concern about the effects of such a change in perspective on their usual work patterns. As part of her negotiation with the hospital, the new Director sought a faculty position at IUMC. She won the position contingent on completion of her doctoral studies.

Department in Transition

This research project began shortly after the new Director of Social Work began her tenure at EEH. It was a significant period of transition for the department. Within the first year of the new administration, the department experienced a 30% turnover in

staff. Several workers retired, one worker died, one was denied continued employment because she failed to pass her Certified Social Worker examination, and one did not return following maternity leave. If this large staff turnover was viewed as a consequence of the new administration, it was seen by the new Director as a necessary "house cleaning" of the strongest adherents of the past administration's perspective. It gave the new Director an opportunity to hire several new workers more sympathetic to her progressive style. Following the retirement of the Assistant Director, the new Director replaced her and hired a second-level administrator. In December, a second Assistant Director was hired. The new administrative structure would enable the Director to implement some of the changes which she felt necessary to revitalize the department, particularly in the areas of staff development and accountability. The skills of the senior staff whom she selected matched her direction for the department.

Apart from the natural change to come about by a new profile in worker tenure and age, specific efforts of the new Director looked towards a department which reflected her personal conception of "professional." This went beyond the educational accomplishments of the workers toward more autonomous and skilled practice, particularly in the realm of mediating organizational problems. Within the conservative culture of EEH, the Social Work Department developed in reaction to the needs of the institution. While other

hospital Social Work Departments in the city had established an autonomous base of practice in dynamic hospital environments, the Department at EEH had not cultivated an institutional perception of an independent professional group within the medical complex. To this end, change in the department in 1985 centered in three areas -- staff development, increased social work autonomy in case finding, and control of discharge planning.

Expanded Staff Development

Consistent with the reactive nature of the previous administration, staff development was limited when the new Director began her tenure. No specific program existed. A structure for worker supervision was in place, but workers were only required to consult with their supervisors on a regular basis for their first six months on the job. After that, they could use the supervisory staff as consultants, as needed. Staff meetings were used primarily for administrative purposes.

During 1985, the new Director appointed a committee of staff members to organize an in-service training program. The committee defined topics of interest and announced a series of lectures for staff development. The Director also made efforts to revitalize the supervisory staff in the department. She used meetings of the supervisory staff to enhance the skills of this level of staff.

She also assumed direct supervision of a small number of staff members. Systems for accountability, peer review, and case finding were previously in place, with written policy and procedures. The new Director informed me that while these procedures existed when she assumed her position, they were not routinely followed by staff, so that adherence to both the form and substance of a high standard of professional practice were lacking. Furthermore, there were several instances where departmental policy as written conflicted with state and federal regulations. The gaps were corrected early under the new administration.

Autonomous Case Finding

Another area designated for change for social workers was autonomy in case finding. The major vehicle for social work referrals at EEH was through the weekly Health Team Conference (HTC). The purpose of the HTC is to anticipate the discharge planning needs of all in-patients on a given service and to share information among staff which pertains to patients' after-care needs. Such meetings typically included the head nurse, social worker, and home care nurse assigned to the floor. House officers are invited to attend HTCs, but appeared infrequently. Particularly during the internship year, house officers select activities which they deem most essential in relation to their

residents and attendings. Health Team Conference meetings are low priority. Social workers use the HTC to report their involvement with patients and describe their progress in establishing plans for patients once discharged. Depending on the relationship among the team members, the meetings might involve substantive discussion about the psychosocial and medical situation of patients as professional colleagues, or since the head nurse typically leads HTC meetings, it could simply be her assignment of cases to home care or social work personnel.

In theory, social workers had been able to offer services to all patients in the hospital. They were not dependent on medical or nursing referrals. In practice, however, there was an informal system of physician control over social work intervention. Particularly in private services, workers did not compromise their relationships with doctors by pursuing cases against a physicians' wishes. This subtle constraint compromised the department's autonomy, as doctors could at times determine which cases were suitable for social work intervention by asking that a private patient not be seen.

Freidson (1970) suggests that a profession's control over its own work is essential in a medical division of labor if it is not to be subordinate to physicians. Clearly, the informal mechanism of case referral indicated the extent to which medical dominance defined social work tasks and enforced its subordinate position.

Both individual physicians and the hospital administration saw discharge planning as the sole function of social work at EEH. Additionally, their conception of this task was limited to the concrete aspects of the job. For the most part, doctors failed to see the need for skills in psychosocial assessment, casework intervention, and systems negotiation which are critical for effective placement strategies.

In mid-1985, the new administration developed high risk criteria for social work intervention. The criteria were intended to focus social work staff on patients for whom social service intervention was particularly indicated. Since these criteria were developed from the social service department's professional norms for workers in hospital settings and did not rely on medical or nursing perceptions of the social work role, they were an effort to enforce social service control over professional activities. In this context, workers would not perform the planning function in response to other professionals' direction. Instead, they could use case-finding strategies to anticipate needs and avoid the problem of being called in too late to implement sound plans.

Discharge Planning

The third area targeted for change was discharge planning. At the time the new Social Work Director was appointed, discharge planning was jointly controlled by the Social Work and Home Care Departments. The previous social work administration had given in to pressure to share this essential task with the Home Care Department. On assuming her position, a priority for the new Director was the return of exclusive control of discharge planning to Social Work. This was achieved by the beginning of 1986. Particularly in the context of DRGs, she felt that discharge planning was an important task for the Social Work Department. Efficient discharge of patients would limit the cost to the institution for patients staying beyond the stated number of days allocated for their diagnosis. If Social Work could have autonomy over discharge planning and avoid cost overages to the hospital, it would establish itself as indispensable to the efficient working of the institution.

The efforts of the new administration were concerned with augmenting the power and professional autonomy of social work at EEH. Since the Social Work Department in the hospital prior to her tenure was submissive to medical authority, her efforts called upon

the line workers to shape a new approach to their work and new relationships with their interprofessional work groups. While many workers voiced enthusiasm about these changes, they challenged old work behaviors and workers struggled with their adaptation in a transitional period.

The Department of Nursing

The work of nurses on the in-patient medical floors focuses on patient care and education. Nursing staff carries out the orders of physicians, which even on private services at EEH are written into the order book by house staff. Nurses are responsible for an array of monitoring functions and dispense medications to patients. With regard to medications, even though the doctors write the orders for drugs, the nurse is legally responsible at the time of administration to assure that the proper drug is given in the correct dosage. Nurses also must be assured that the patient is in proper condition to receive the medication. In most respects the nurse is the most directly accessible health professional to the patient. Nurses have the most frequent and intimate contact with patients. The nurses, particularly the head nurse on any given service, seem to run the floor. Especially at the beginning of the academic year in July, nurses are acutely aware of their organizational knowledge and how dependent the new crop of house

officers are on them for important information about hospital procedures. It is obvious to individual nurses that a critical function of the nursing staff is the acculturation of house officers to floor life. They use their greater knowledge of the operations of floor life to socialize doctor-trainees.

Nurses play a critical role in determining the needs of patients at the point of discharge from the hospital. They have the best information on the patient's functional capacity and the specific care needs which will follow patients into the community. The head nurse is at the center of the Health Team Conference. Before the efforts of the Social Service Department to anticipate case finding, head nurses frequently acted as gatekeepers for referring patients for social work service.

During the period of the study, the Department of Nursing at EEH severely tightened administrative accounting procedures on the floors, and also vigorously pursued cost containment efforts in nursing. Nurses on medical floors met these efforts unhappily since they added considerable time pressures to already difficult work. Nurses found that they had more paper work to complete for the administration and fewer staff members assigned to each shift. Several head nurses were outspoken about locating the source of these problems in a new Nursing Administration, which some felt was specifically hired as a group from another institution where the nursing budget had been reduced. Nurses complained vigorously that

the nursing administration did not understand the nature of their work, never appeared on the floors, and did not support nursing needs to the hospital administration.

Certain practice areas in nursing benefit from in-service training, work usually performed by nurse practitioners who are clinical specialists with specific expertise. Among the most serious complaints of staff was the lack of support for the work nurses had to perform with numbers of patients with cancer or chronic illness. The fact that the nursing administration would not carry the half-salary of the clinical specialist in supportive care was a striking example of their disinterest.

For all professional groups studied in this project, the study period was a time of institutional change within the hospital and medical complex. The Departments of Social Work and Nursing each underwent recent changes in administration, with very different agendas for their service areas. Significant changes in the wider health care environment also affected the work of doctors, nurses, and social workers.

Changes in the Context of Health Care

According to Freidson, "it requires no special perception to see that health care is going through massive changes in the United States" (Freidson 1985, 11). Prior to World War II, doctors

practiced their craft in their own offices, with considerable autonomy. They admitted patients to hospitals with the expectation that health workers would carry out their orders. Accelerated change in the health care system followed enactment of Medicare and Medicaid legislation in 1965. The new laws heralded an era of expansion in medical care in the United States. Increased government spending on health care translated into a shift in power to large medical centers. Health occupations multiplied, technology expanded, and large hospital administrative structures evolved with elaborate requirements for record keeping and accounting systems.

Efforts by the Reagan administration to contain health care costs began to cap the power centered in traditional health delivery complexes. The effect of these policies on hospitals was already shown during the study period by a decline in occupancy rates, which fell by 7.8% in 1985, the steepest decline in twenty years (The New York Times April 16, 1985). The impact of cost containment policies suggested changes for the individual physician in practice as well, with increasing numbers of physicians and incentives for capitated prepaid medical practices.

The year during which this study was undertaken, 1985-86, was a particularly critical one for EEH-IUMC. While EEH had resisted changes in care delivery in past years, recent health care trends forced the institution to deal with significant issues over which

it had little control. Two such issues raised concern about the impact of dying patients in-house. First, the hospital anticipated billing in January, 1986, a flat rate of reimbursement based on the type of case rather than days spent in the hospital. To all departments this signaled the need for cost containment, increased productivity, and a justification of function among paraprofessional personnel. Second, in 1985 EEH, along with other big-city hospitals, treated a sizably increased number of patients with acquired immune deficiency syndrome (AIDS). Nurses, social workers, and house officers were responsible for the day-to-day care of this population of primarily homosexual and bisexual men, all with the inevitable prognosis of death. These simultaneous events brought new sources of strain to terminal care in hospital settings. Finally, beginning in 1983, the death awareness movement culminating in the passage of a Medicare reimbursement benefit for hospice services helped focus public awareness on several ethical and practical issues in terminal care. This affected the daily lives of hospital staff.

Diagnostic Related Groups

During 1985, EEH anticipated the changeover to Diagnostic Related Groups (DRGs) which was scheduled to begin January 1, 1986. In 1983, Congress adopted this new method of payment for

Medicare services to provide incentives for cost-containment in hospital care. Prior to 1983, Federal as well as private insurance reimbursement for medical services was determined by the total bill at discharge. Under the new system, hospitals are paid a set price for their Medicare services. The fee is determined by the average cost of treating a patient with a particular diagnosis. The Health Care Financing Administration established 468 groups for Federal use in this program. They form the basis for DRG-determined rates through an equation which determines the prospective payment rate. Hospitals will not be paid more than this amount even if the actual costs in treating a patient are greater (See Vladek 1984). Described as "counterrevolution in financing health care," (Dolenc and Dougherty 1985, 19), DRGs were seen by some as a threat to widespread access to quality medical care and to the development of new medical technologies spurred by the Medicare and Medicaid legislation.

Hospital personnel at EEH anticipated the introduction of DRGs with anxiety. They prepared for the expanded authority of the Utilization Review staff, which was renamed "Case Management." Previously, Utilization Review (UR) had considerable clout regarding patient stay in-hospital. Because UR monitored reimbursement patterns by third-party-payment sources, they could control the discharge process. Doctors, nurses, and social workers had established methods to keep desirable or medically needy

patients in-house or to rid themselves of undesirable patients. Physicians commonly shared code words for chart notation which documented the stay in a way acceptable to the UR nurse and the funding source. Nurses and social workers discussed the strategies During HTC rounds to subvert UR nurses' efforts to get patients discharged.

A new system for monitoring hospital stays meant workers faced a revision of established strategies. Because they felt the DRGs would pose more stringent regulations, they anticipated more limited opportunities for bending the system. Apart from changes in work patterns which concerned staff, hospital personnel also questioned how the regulations would affect specific patient populations. Certain patients would clearly benefit the hospital financially, while others, likely to require longer stays than the prospective payments allowed, would be costly. The basically healthy surgical patient who was hospitalized for a discrete procedure, such as a cholecystectomy (a gallbladder removal), would be an economically beneficial patient. Seriously ill patients -- such as end-stage cancer patients -- would be less economically beneficial, since their stays in the hospital might linger beyond what could be documented for reimbursement. Practitioners wondered whether the hospital could continue to provide palliative care to terminally ill patients previously admitted for supportive care and pain control.

In addition, intensification of concern over cost containment in health care introduced a new element to the complex question of the prolonging of life through medical intervention. A calculus which previously involved the odds for survival, fears of malpractice suits, family guilt, and personal ethics now included even tighter limitations on health care resources. An article in the New England Journal of Medicine entitled "The Care of the Terminally Ill: Morality and Economics" reviewed aspects of this problem, particularly the conflict between institutional responsibility and clinicians' commitments to individual patients (Bayer et al. 1983). This issue is particularly complex, since cost containment efforts effectively dilute the power of the individual physician and, perhaps, professional values as determinants of clinical practice.

The Impact of AIDS

Background

Acquired Immunodeficiency Syndrome (AIDS) was first identified in the United States in 1981. Thought to be a new disease, AIDS is the end point of a spectrum of illnesses which result from infection with the human immunodeficiency virus (HIV). AIDS attacks the immune system of previously healthy individuals,

leaving them vulnerable to serious disease such as Kaposi's Sarcoma and a variety of severe opportunistic infections, the most prominent being _Pneumocystis carinii_ pneumonia (PCP). Given present therapies, AIDS is considered inevitably fatal although new anti-viral drugs have proven effective against some opportunistic infections and can be used to delay the onset of these infections in individuals. In fact these drugs prolong the lives of HIV infected individuals who are asymptomatic.

AIDS was first identified in homosexual and bisexual men and shortly after in intravenous drug abusers. The largest numbers of AIDS cases are still found in these two groups. This disease is spread through sexual contact with an infected partner and through contact with tissues or blood of an infected person. It can be transmitted _in utero_, and from infected men to female sexual partners, as well as from infected women to male sexual partners.

As a new, contagious, and at present incurable disease, AIDS has drawn considerable public attention. Particularly in the large coastal urban areas where the disease is presently concentrated, this illness received remarkable attention in the press. Not only was scientific information frequently reported to lay and professional audiences, but the complex responses of the community could be observed in the almost daily spate of newspaper articles which appeared about AIDS during the period of this study. For example, the question of whether children with AIDS should be

allowed to attend public school was frequently aired in city newspapers and television programs and widely debated in editorial columns and letters to the editor. Ambiguous reports about the possibility of transmission of AIDS through casual contact also appeared during this time. It would be difficult to imagine an adult in the city in this period who was not exposed to the wave of anxiety generated by the illness. The wide circulation of AIDS jokes in the early stages of public awareness and the more lasting changes in homosexual life-style were other manifestations of this anxiety.

The Impact of AIDS on Health Professionals

As described in Chapter One, AIDS had considerable impact on the work, training, and emotional resources of health professionals in teaching hospitals with large numbers of these patients (Wachter 1986). Hospitals such as EEH, located in cities with large homosexual populations, were particularly affected. A resident at San Francisco General Hospital, a major center for the care of AIDS patients, described the impact of the disease on the training experience of his cohort as a limiting factor in their residency training (Wachter 1986). For house officers training in these institutions, AIDS dominated the content of their conferences, teaching rounds, and reading. AIDS therapy is frequently

undertaken through research protocols, so that the input of house officers on the care of these patients was limited. Since the development of autonomous practice is one of the most critical elements in a house officer's professional growth, the lack of input was seen as a deficit in training (Wachter 1986).

A resident in the first cohort of physicians to treat AIDS patients as house staff in four training institutions in New York reported an increase in anxiety and stress among all groups, as well as the fact that many young physicians intended to avoid work with AIDS patients in the future and did not believe it would be unethical to do so (Altman, 1987).

Wachter (1986), himself a resident working in San Francisco in the first years of the AIDS epidemic, described the emotional issues house officers face in dealing with AIDS patients. These included fear of transmission, frustration with the technical limitations of treating a young and terminally ill population, and association with the stigmatized populations of homosexuals and IV drug users. These responses can be generalized to other health workers who care for these patients. The rapid influx of patients with the disease strained institutional and individual resources at EEH, as the hospital was hard pressed to provide the extensive hands-on care required by these very sick patients. Minimal staffing within the hospital, combined with limited possibilities for community support, only exacerbated the emotional toll presented by the disease.

The Hospice Legislation: Culmination of the Death Awareness Movement

A proliferation of scholarly and journalistic articles on the subject of death followed Feifel's seminal work, The Meaning of Death (1959). Two physicians were particularly influential in this movement: Elizabeth Kubler-Ross (1969) for her clinical description of the stages of dying and Cecily Saunders (1960) for advocating the hospice model of care for dying patients. These women were at the center of a compelling grass-roots effort to humanize terminal care and to bring to the death experience an openness which allowed for the acceptance of a natural event in life. Based on the literature of the 1960's and 1970's; reviewed in detail in Chapter One, considerable evidence existed for a lack of openness about death in medical practice. According to normative practice standards of the times, patients were not adequately treated for cancer pain, and they were not told about a poor prognosis. Doctors and nurses were described as avoiding dying patients or applying curative techniques when they had no benefit. The humane application of increasingly sophisticated technologies, especially life-sustaining technologies, was a major focus of the movement.

The Hospice Movement in The United States

Hospices developed with remarkable fervor in the United States

in the mid-1970's as an alternative to traditional hospital care for the dying. They were designed to meet the specific needs of dying people and their families for psychosocial support and palliative intervention. Hospices proposed an acceptance of death which contrasted sharply with the death-defying efforts seen in acute care hospital settings. More than any program model, hospice was a philosophy of care which put into action the ideals of a social movement.

The enactment of Section 122 of the Tax Equity and Fiscal Responsibility Act of 1982 brought Medicare reimbursement to hospice programs. On April 8, 1986, President Reagan signed a law repealing the "sunset provision" of the Act, making the benefit permanent under Medicare. The enactment of the law legitimized the hospice philosophy and brought public recognition to efforts of the previous twenty-five years to humanize death. After four years of hospice under the Medicare umbrella, a minuscule proportion of the Medicare budget was spent for hospice care. Given the projected numbers of terminally ill cancer patients eligible for Medicare, only a very small proportion of that group opted for the benefit. Since 90% of hospice patients are cancer patients, this is a good indicator of the lack of utilization of this program (Lukashok 1987).

For sophisticated medical centers, such as EEH, the impact of the hospice and death awareness movements extends beyond providing

a programmatic alternative to traditional terminal care. The influence of the two movements is evident in teaching hospitals where the stages of dying are taught, along with the promotion of adequate doses of narcotic medications for metastatic cancer pain. These movements have also highlighted the complex ethical and pragmatic problems generated by a continuing stream of technical advancement in medical care. The impact of hospice concepts on terminal care observed at EEH will be discussed in later chapters.

Developing Guidelines for Applying Life Sustaining Treatments

Specifically, the hospice and death awareness movements created a climate for public discussion of the impressive potential for medical technology to forestall death, with frequent disregard for its inevitability and naturalness. In 1976, the publication of two articles and an editorial in The New England Journal of Medicine (Rabkin, Gillerman, and Rice 1976, Critical Care Committee of the Massachusetts General Hospital 1976, and Fried 1976) sparked discussions in the mainstream medical community on the need for explicit policies for limiting life-sustaining treatment. These articles described informal practices in the nation's hospitals which applied or withheld such treatments without formal guidelines. Although life-sustaining treatment encompasses an array of potential medical interventions, including the use of

ventilators, vasopressor or antiarrhythmic medications, do-not-resuscitate (DNR) orders have become a paradigm for the public debate on withholding these treatments (Younger 1987).

Cardiopulmonary resuscitation (CPR) is a specific lifesaving technique, applied when a patient has a cardiopulmonary arrest. It involves external chest compression and some form of artificial respiration. CPR is a dramatic act, because intense and rapid activities surround the "code;" it can bring a patient back to life after the traditional signs of death are already apparent. Because of the potential for a wide utilization of this technique, its invasiveness, and its frequent failure, informal ranking of patients to be or not to be resuscitated developed in many centers (Younger 1987).

In 1984, the year in which this study began, a grand jury in Queens, New York, reported that La Guardia Hospital, a small community hospital, had a policy for issuing resuscitation orders which involved placing colored dots on nursing records. The orders were not discussed with family members (The New York Times March 24, 1984). In another event during the course of this study, a house officer at a large teaching hospital was charged with failing to resuscitate an 87 year old patient who suffered a heart attack (The New York Times May 10, 1985). The climate of uncertainty about resuscitation in a period of rapidly developing public policy formulation left the house officers and nurses on the line with an

acute awareness of their vulnerability along with a lack of direction for their activities with dying patients. Although efforts at clarification soon followed these events, the direct care providers worked in a context of ambiguity and uncertainty about the consequences of their actions.

Health care transitions which occurred during the study period had direct consequences for hospital management of the dying. These events colored the work experience for staff with their terminally ill patients. The public discourse on DNR orders, the impact of DRGs on the availability of palliative interventions, and the profound emotional and work demands of caring for large numbers of AIDS patients intensified concerns about the nature of death work for hospital professionals.

The Author's Position in the Setting

In September, 1983, I was recruited as a Research Aide in the Division of Clinical Pharmacology at IUMC. I was contacted by a medical sociologist who was a consultant for the Supportive Care Service (SCS), a service activity of the division. The medical directors of SCS wanted to employ a graduate student interested in using the hospital as a site for a field study. They sought a doctoral candidate who could help with research projects in exchange for access to the site and a small stipend.

The Author's Relationship to the Supportive Care Service

The SCS is a consultation service for terminally ill cancer patients hospitalized at EEH, modeled after hospice concepts of care (appendix 1). At the time of my initial discussions with the SCS Directors, the service was a multidisciplinary team which accepted referrals from attending physicians for symptom management and psychosocial support of their dying patients. The team consisted of a nurse coordinator, a clinical medical fellow, and the two physician directors of the service. Social workers were involved on a case-by-case basis, as patients they serviced were referred to SCS. They were invited to attend SCS rounds where they presented psychosocial background about their cases.

In November, 1983, I was hired to assist the Supportive Care Service and the Division of Clinical Pharmacology, with research projects in the area of pharmacological pain management. I was paid a stipend for half-time work, with the expectation that the division facilities as well as the hospital staff and patients would be available to me for my dissertation research.

The Supportive Care Service was a small unit within the Division of Clinical Pharmacology. Most of the work carried out by the division was in biomedical research, such as kinetic drug studies, or clinical trials of drug efficacy or side effects. The Supportive Care Service and pharmacology consultation were

considered a very small part of the division's productive work. They were described by the division head as the "service components" of the division's activities. Since the basic financial support for the division came from NIH grants or from large drug companies for clinical trials of their products, SCS's financial contribution to the unit was limited.

As research aide for the SCS, I attended bi-weekly Clinical Pharmacology teaching rounds, weekly SCS rounds and bi-monthly Clinical Pharmacology Division luncheons. I was invited to all lectures, dinners, and social events sponsored by the division and the department. I was given desk space in both the SCS and division offices and had access to two IBM dedicated word processors and office supplies.

My contribution to the research efforts of the division and the SCS changed over the two-year period from employment through completion of the data-collection phase of this study. Initially I assisted the SCS in developing an instrument to measure pain, mood, mental status, and psychomotor functioning in metastatic cancer patients referred to the SCS for symptom management. Once the interview format was established, I saw all SCS patients at least bi-weekly to perform the assessment.

I volunteered to assist the SCS team with various aspects of their work. For example, I discussed research-in-progress with the clinical fellow, or offered to transmit messages to patients or

staff on behalf of the nurse coordinator of SCS. When the Clinical Pharmacology Division began its study of mental status changes and chronic narcotic administration, I administered the assessment to patients as bloods were drawn from these patients to measure narcotic levels. I also surveyed the medical and surgical floors in the hospital for appropriate study patients. While the assessment was not used to collect data for this study, the process of identifying terminally ill patients provided contact with many of the health personnel who are the focus of this project. Also, my contact with SCS patients and their caregivers during this period provided me with most of the observations made for my own research. This process will be discussed at greater length in the next chapter.

The Decline of The Supportive Care Service

During the period from my initial employment with the SCS through completion of the data collection phase of this project, the SCS underwent a significant decline in staff and patient referrals. By the time I completed the data collection phase of the study, the service lost both the nurse coordinator and the clinical fellow. The nursing administration failed to assume the nurse's salary as it had promised, and the clinical fellow left after completion of her two-year contract. She was not replaced.

The loss of visibility and manpower led to a significant drop in the number of referrals, particularly from staff nurses, who had been the main source of referral for SCS patients. A combination of austere times within the hospital, lack of effective institutionalization of the service, and the team's isolation from the mainstream of acute care hospital work converged to precipitate the decline of the SCS.

In spite of the diminished position of the SCS in the hospital, my work with the SCS and in the division gave me exceptional access to the hospital medical complex and a high level of acceptance by all staff and patient groups in the hospital and medical college. During the entire period of the study, I was extremely visible on the inpatient medical floors at EEH. Identified as a researcher for SCS in my contacts with medical and nursing personnel, I was introduced to the medical and surgical social work staff as a doctoral candidate in Social Welfare. I presented SCS research methods to this group's administrative meeting and described my doctoral study at two Social Service staff meetings during the course of the study. My hospital identification badge read "Pharmacology" with no indication of title or degrees; hospital personnel interpreted that designation in any number of ways.

Opportunities for Observing Terminal Care

My position with SCS provided a unique opportunity to observe systems of care for terminally ill patients in-hospital. The structural ambiguity of my position gave me access to many levels of hospital personnel. Line social workers and social work administrators, as well as nurses, medical students, house officers, attendings, and the medical directors of SCS openly discussed their personal impressions with me. I was able to accumulate a remarkable store of information about the informal operations of the institution. During the data collection phase of the project, hospital staff were available to me for interviews. They were apparently candid in their responses. My attractiveness to staff was enhanced by the fact that they have little opportunity in the course of their work to discuss problems in care of the dying. Many professional groups and levels of staff welcomed the opportunity to speak about this difficult aspect of their work.

Supports in Study Implementation

The political clout of the SCS medical directors and the enthusiasm of the new Director of Social Service for this project greatly facilitated the implementation of this study. One of the medical directors was the head of the Division of Clinical

Pharmacology in the medical school. The other director was educated and trained at IUMC. He had been an attending physician at the hospital for over twenty years and was a respected physician in the hospital community. The fact that the study was conducted under their auspices enhanced my position with nursing and medical staff. These physicians were not only respected by their medical colleagues, but are well known to Nursing and Social Service Administrations, who viewed them as sympathetic to patient care concerns and therefore "good Docs."

The new Director of Social Service supported my doctoral project and encouraged staff participation in it. A student in the same doctoral program, she was interested in the process of implementing the dissertation study. Also, she was enthusiastic about the topic since it had been a longtime interest of her own. Having a social worker in the hospital conduct research had the advantage of demonstrating the research interests of social workers to hospital personnel. At the same time, since my work was sponsored by the Department of Medicine, she was not required to spend resources from her department to reap this benefit. As a result, she encouraged her staff to identify patients for project participation and to be interviewed themselves. In this way, she was able to expose her staff to social work research during a period in which she hoped to stimulate their own research interests.

Problems in Implementation

While virtually the entire Clinical Pharmacology/SCS work group supported completion of this project, impediments and conflicts did exist. An underlying issue was the disparity between the norms of the divergent occupational cultures of medicine on the one hand, and social work and social science on the other. Occupational subgroups form their own sets of goals, values, language and technology. This results in each group organizing the facts in terms of its own world (Cottrell and Sheldon, 1963). As Cottrell and Shelton (1963) describe the cultural coflict between physicians and social scientists, doctors are trained to see individual organisms or segments of them, while social scientists tend to conceptualize problems in terms of interrelationships among organisms.

One specific manifestation of this disparity was the generally negative attitude about social science research and/or about social work held by the group of physicians and biomedical scientists at the hospital. One medical director regularly introduced me as a "sociologist" and never referred to my social work experience. The other director spoke to me about "shoddy methodology" in a previous doctoral project conducted at EEH by a Social Welfare doctoral candidate. These comments reflected a lack of enthusiasm for the professional discipline in which the study was undertaken and a

bias towards basic science and clinical medical research as a standard for research in other areas. Clearly, the research model of this study was very different from the rigorous quantitative, double-blind, controlled research methodologies which are the norm in this setting. This negative attitude toward naturalistic, qualitative research methodology left me bereft of collegial support throughout the conduct of the study. Social work and nursing staff also required interpretation of the methodology of this study since they too were more familiar with quantitative reesearch.

Conclusion

In this chapter I have presented the organizational and historical context in which this project was undertaken, and I described my position in the study setting. I reviewed the organization and culture of this large university-affiliated teaching hospital, with particular attention to the Medical, Nursing, and Social Service Departments. Since social workers were the principle informants for this study, and their Department underwent all the changes attendant to a new administration coming in during the study year, these changes were described in detail.

Health-care institutions in the city and EEH in particular dealt with, and continue to respond to, extrinsic pressures on

their resources and community. Among the strains affecting EEH during the year of the study, DRGs and AIDS were problems in critical areas of the care of terminally ill patients. These two contextual issues, along with public discussion on ethical and legal problems surrounding resuscitation, sharpened the issues of terminal management in acute care hospitals. DRGs reduced the already limited resources of these hospitals to do this work, while AIDS increased the institution's responsibility in the area of terminal care. Ambiguity about the application of life-sustaining interventions provoked uncertainty about medical management of the dying for professionals on the line. These themes were reflected in the observations of staff who were the subjects in this study; interviews with staff further bore out these themes.

CHAPTER THREE

METHODOLOGY

Introduction

In January 1984, I began working as a research assistant for the Supportive Care Service (SCS) at East End Hospital (EEH). Housed in the Division of Clinical Pharmacology of the Ivy University Medical College, this multi-disciplinary consultation service, a subcommittee of the Medical Board of EEH, treated the immediate symptoms and psychosocial problems of patients dying of malignant disease. In exchange for assistance in the research activities of the service, I received a stipend and had access to the medical complex for a dissertation research project.

House officers, nurses, and social workers came to accept my presence as a member of the SCS team and cooperated with my research on their work with the dying. The position gave me an exceptional degree of visibility and acceptability to staff, along with an ambiguous status which I was able to exploit to develop rich empirical data about this problematic area of hospital practice. My work with this group eliminated many of the problems

of access reported about social science field work in hospitals, including areas which are generally closed to the outsider (Bosk 1967). This affiliation provided an excellent opportunity to mount a qualitative study of the relationship between health professionals and terminally ill patients in their care, using participant observation and interview methods. After a year of observing the operations of the SCS and the structures for care given the dying on inpatient floors at EEH, I focused this study on describing health professionals' definitions of "good" and "bad" dying patients, and targeted my observations and interviews on patient-staff interaction.

In this chapter, I will discuss "grounded theory" (Glaser and Strauss 1967) as the methodological basis for this exploratory study and describe the process through which evolving qualitative data were funneled into several emerging areas for theory development. I will describe my role as participant observer and the use of focused interviews for the purpose of data collection in this field study. Finally, I conclude with a review of the institutional approval process which allowed for the study and case selection.

Advantages of Qualitative Methods for this Study

Epstein (1985) describes the continuing bias in favor of

quantitative methodology among social work researchers. In spite of the disproportionate number of quantitative studies appearing in the social work literature, he points out that both qualitative and quantitative methodologies each have advantages and disadvantages, and that the researcher's choice should depend on the research context and focus, previous knowledge, and theory development in the substantive area (Epstein 1985).

Qualitative methodologies tend to be descriptive, inductive, and subjective. Their value is in describing a social reality with empirical richness and in generating -- not testing -- hypotheses. They are most suitable where the researcher has little control over the structural aspects of the setting. These methods have the advantages of unobtrusiveness and flexibility, and are able to capture a subjective reality from the perspective of the people involved (Epstein 1985). Thus qualitative methods were appropriate for this project because of the complexity of hospital setting and the goal of describing the experience of caring for terminally ill patients from the point of view of those providing hands-on care. Quantitative methods, such as surveys or structured interviews, can superimpose the perceptions of the investigator on the study population so that the subjective experience of those groups studied may not be revealed.

In investigations of the work of hospital professionals, forced response instrumentation can foil the intent of the investigator.

Much of the work of doctors, nurses, and social workers takes place behind the scenes, and health professionals are adept at obscuring their own reactions to their work behind well-polished professional personae. Socialization to normative standards of professional behavior for these workers forces the negative and ambivalent responses of care givers underground to informal interactions; these are kept closely guarded from the outsider. Structured interviews or forced-choice surveys cannot penetrate routinized, formal responses. Since my intent was to capture the work realities of medical staff, methods which allowed me to probe informal interactions were more appropriate.

Another advantage of qualitative methods for this study was the nature of the study setting, a dynamic medical center. Workers in the complex and demanding world of inpatient hospital care have many time constraints. A qualitative design allows the researcher to take into account the pace and timing of the workers' tasks, rather than impose a time frame on informants. The low response rates to surveys of medical personnel in some sensitive areas of professional practice may be due as much to the limitations on health worker's time as to the sensitivity of the topic. Since I was a participant in the setting, I was able to take advantage of events as they occurred. With focused conversations, I could ask questions about the observed activity.

In sum, qualitative methods best served the intent and context

of this project, for both practical and substantive reasons. They allowed me to study hospital professionals without disrupting their highly structured and demanding work routines. They also allowed me to capitalize on life-events as they occurred in the field.

Grounded Theory

Glaser and Strauss (1967) describe "grounded theory" as a method by which theory is induced through empirical observation. This model provided the theoretical basis for this study of hospital workers' responses to terminal care. As an inductive process, this method of theory development relies on what the investigator learns about the experience. Theoretical propositions emerge from the data instead of the data being used to test previously generated propositions. Hence, the research effort is a process of discovery and reformulation. As new data are collected, the researcher shapes further investigation by focusing on the most promising material to develop from the field (Glaser and Strauss 1967).

The term these authors use to describe the process of generating theory from data, and using illustrative characteristic examples to present the theory, is Theoretical Sampling. In theoretical sampling, the research is guided by the theory that emerges as the data are collected, so that the analyst must

simultaneously collect, code, and analyze data. In generating grounded theory, the initial decisions about where to begin data collections are based in a general way on the existing sociological literature. Unlike the application of deductive methods, however, initial research decisions are not based on a preconceived theoretical framework. Rather, the process can begin with a partial framework of logically-related concepts. Then, as concepts are uncovered, emerging theory develops; this points to the next steps. The researcher does not know where these steps will lead until s/he identifies gaps in the theory, disparity between observations in the field and existing theory, or by research questions suggested by previous answers. It is important for the developing process that the researcher does not see the categories as rigid, but remains open to respond to unanticipated insights from new evidence. These authors strongly suggest establishing comparison groups, which are ideally selected for theoretical purpose and relevance (Glaser and Strauss 1967).

The grounded theory approach was exceptionally well-suited for this project, primarily because it allowed the hospital staff to describe their experience in a direct way, both through their actions and through responses to a focused interview. For example, because professionals were asked to identify "difficult cases" in their own practice, they defined problem patients by their own selection criteria. Their responses to interview questions about

these problem patients became the indicators for difficult terminal cases. Ultimately, through an ongoing process of conceptualization and analysis, these became categories of both problematic and ideal patient types, which I present fully in the next chapter.

As the study progressed, it became clear that some long-standing empirical knowledge about terminal care had been affected by recent events in health care, particularly the values of the hospice movement and the influx of increasing numbers of AIDS patients. Since the initial theoretical framework for the study was based on a review of sociological literature which predated the impact of these events, discrepancies between these formulations and the reports of informants emerged. As these discrepancies became apparent, I was able to reframe some of the formulations developed for this project, and track down the sources of these changes.

The ability to follow up interesting theoretical leads shaped the project in other ways. For example, the repeated suggestions of staff members that AIDS patients would provide interesting material for a discussion of problems in terminal care opened up the possibility of a theoretical sampling strategy comparing this group of patients with metastatic cancer patients. As a result, there were several reasons why a grounded theory approach was especially suited to this study. First, the level of theoretical development; second, the historical impact of changing health care

perspectives on the dying; third, the natural comparison groups of AIDS and metastatic cancer patients, which were added to originally planned comparisons among the three professional groups in this study.

My Role as Researcher

The principle methods used for data gathering in this project were participant observation, focused interviews, and purposive conversation, all described in the literature on qualitative research (Spradley 1980). As indicated earlier, these qualitative methods took advantage of my unusual position in the setting, and also exploited that advantage with the least disruption to the care-giving system. I was perceived by all personnel as an insider rather than an outsider, reducing validity problems. I scrupulously informed workers about the purpose of my questions and they responded to me as a colleague, with unguarded and candid replies. This candor was evident even during the scheduled interviews, where the responses were tape recorded. Only two informants initially offered "canned" responses to my questions, but even these guarded reactions abated as the interviews progressed.

My special position in the hospital allowed me to make effective use of the relationships I had with informants from the

field in order to elicit data. My role conformed to Pearshall's label of "participant-as-observer" (Pearsall 1965), and allowed me to penetrate beneath the surface of public behavior and superficial expression.

My exceptional level of access was further enhanced by my role with the SCS, which was ambiguous to those in the group and to other health professionals. Because my name tag identified me only by my name and division, most professionals with whom I had contact did not know my discipline on first meeting. In most instances, I was identified with the professional group with whom I was traveling the corridors. During teaching rounds, house officers often directed questions to me as a physician, and when I was seeing patients with the nurse coordinator, nursing staff assumed I was a nurse. Their comments revealed a level of intimacy and assumed understanding on my part that would normally be expected among peers. As my tenure with the service grew, more staff knew about my position with the service and also about my doctoral study. By that time, however, I had apparently gained collegial acceptance from nursing and medical staff. Social work staff always identified me as a colleague.

The process of over-identification with study subjects is sometimes described as "going native." In this study, my identification with the correlatives may have, in fact, introduced bias in the sampling process and in my objectivity as an observer.

As I developed a working relationship with many of the men and women who were informants for this study, I began to construct my own ideas about the work. Also, I developed a special affinity with some colleagues and not with others, so that ultimately more friendly workers would suggest more patients to discuss. Additionally, I was more likely to gravitate towards "friendly" sources for observations.

My job with SCS included care-giving functions which led, in turn, to identification with the care givers I was studying. Even though my function with SCS patients was to assist in the research efforts of the service, all members of the team were defined as "care givers" to the patients, a carry-over from the hospice model. Because the group saw all patients at least once, and in some instances, several times a day in a care giving role, detachment from that relationship with patients was exceptionally difficult.

Bruyn's (1970) comments that the participant observer role requires both detachment and personal involvement captures the essential problem with carrying out this field method, and is a particularly apt description of the dilemma I confronted in my dual roles as researcher or SCS staff member. In an effort to maintain my objectivity, I closely monitored my own responses and tested evolving concepts and propositions with experts both within and outside the hospital community. To insure that I was not

unwittingly producing a biased sample of "problem" patients, I continued to solicit cases for interview purposes until all members of the social work staff had volunteered at least one case. In this way, I hoped to lessen the possibility of case-selection bias, at least with the professional group I most depended on for subject referral. In any event some social workers quickly referred cases, and in two instances made multiple suggestions. Other workers were more resistant, so that towards the end of the project much of my subject finding effort was directed at two resistant social workers.

A second related impediment to participant observation was the ambiguity of my role within the SCS. Although the "research aide" position would usually be confined to specific work tasks directed by the principal investigator, this was not true in my case. The fact that I was a doctoral candidate carrying out my own study, and that I was also a trained social worker with clinical hospital experience led to confusion among SCS staff about how they might use me in the service. This issue was exemplified in the SCS director's perception that I was going to make the service itself the object of study. He frequently asked for my analysis of current problems with the SCS. Another consultative area in which he sought my advice was fund-raising.

The lack of clarity about my job definition led to discussions with the director in which he outlined his own perceptions of

institutional problems related to the management of dying patients. In this way, however, he inadvertently provided a useful analysis about terminal illness from the point of view of an established physician. Yet, these discussions smacked of indoctrination, or at the very least socialization, which took massive efforts on my part to neutralize. Recording these discussions as observations was one such effort. Additionally, I tested some of the director's perceptions with other staff outside the service, or evaluated them against empirical evidence based on my own observations. For example, the director maintained that because of the efforts of the SCS program, house officers employed good basic knowledge about therapeutic principles of pain management for metastatic cancer pain. Yet when cases were referreed to the SCS, a commonly observed response to uncontrolled pain was for house staff to make frequent changes in the narcotic drug and dose, often made too quickly to discern whether or not the previous dose had a therapeutic effect. Discussions with other physicians revealed other sources for house staff education about cancer pain treatment, such as private oncologists or powerful information about therapeutics provided by more senior house staff (Mizrahi 1986).

Besides the SCS director, other professionals used my interest in this area of their work as an opportunity to discuss their perspectives on terminal-case practices in this institution. The

SCS nurse coordinator and clinical fellow, as well as many house officers, social workers, and staff and head nurses discussed issues with me during the course of the study. These conversations were logged as field notes.

Discrepancies between observed behaviors and subjects' reports in purposive conversation or interviews are commonly noted in research which employs these methods. Pollner identifies these occurrences as a "reality disjuncture," (Pollner 1973, 116) which calls for a closer examination of the discrepancy. Certain discrepancies noted in this study had political sources. For example, what the SCS directors told benefactors might be censored for fund-raising purposes. Another category of discrepancy involved differences between "back stage" and "on stage" behaviors, commonly observed in this study. Most notable, house officers and nurses would frequently use language and affective styles at the nurses' station which were never observed with patients. Finally, some disparities presented clear contradictions between observed behaviors and informant statements, and may in fact have been unconscious. For example, during a referred consultation, the SCS director skirted direct discussion about a patient's prognosis while in the presence of her family. The family did not want him to respond honestly to the patient's persistent probes about her condition. In a later interview, he told me he had in fact answered her questions directly. To some extent, the verbal

interpretations of ambivalence appeared to be a way of rationalizing equivocal behavior.

In summary, my role of participant observer permitted me to penetrate below the surface and public behavior of the medical personnel studied, to the beliefs and behavior of these workers in their natural environment. Focused interviews allowed me to follow specific theoretical leads that derived from analysis of the observational material and to probe disparities between what was said and what was observed. In the context of my employment with the SCS, I was exceptionally well situated to carry out this study, in spite of the risk of "going native."

Project Approval and Staff Cooperation

Institutional Approval

In order to conduct this study of health worker's responses to terminally ill patients in hospital, I needed institutional approval, not only to assure that I would be free to use the observations gathered in the setting, but also for access to health workers for interviewing. The formal approval mechanism for research studies conducted in this medical institution is the Human Rights Committee (HRC). The HRC must review all research projects conducted in the hospital and medical school to assure that the

studies conform to government and hospital regulations governing such activities.

For most investigators, the approval process begins with the submission of a form describing the project. This written protocol includes form and procedures for gaining informed consent and for protecting confidentiality of human subjects. In the case of animal studies, it includes statements about how the rigorous standards for caring for animal subjects will be maintained. While primarily a means for assuring that research is conducted in an ethical manner that conforms to legal requirements for such studies, the HRC also passes on the scientific efficacy of projects run in-house.

One of the SCS directors sat on the HRC during the time I began this project. At his suggestion, we jointly submitted a letter to this committee outlining my position in the Division of Clinical Pharmacology, the proposed methods for the study, and the means of obtaining consent from the hospital professionals to be interviewed (see appendix 2). I was thus able to expedite the HRC procedures and obtained the sanction of the committee to proceed within a short time. In addition, I was able to start my research promptly and effectively since the HRC approval smoothed my access to the administrative and professional staff. This turned out to be an especially important step, as several informants and administrators questioned whether or not the research was HRC approved.

Social Work and Nursing Approval

I also obtained separate administrative approval from the Departments of Nursing and Social Work. Obtaining such approval from the Department of Medicine for house staff participation was not necessary. Because of the presumption that physicians practice autonomously, their decision to participate in such a study would be self-governed.

Predictably, the Department of Social Work was the most supportive of this research project and was actively involved in its implementation. As mentioned earlier, the new director of the department was also a student in the doctoral program and had a long-standing interest in terminal care. She saw an opportunity for demonstrating social work research to her staff without having to expend resources from her department. As part of my efforts to familiarize the staff with the project and also attract cases, I met with the complete social work staff on two occasions and with the smaller group of eight medical and surgical social workers twice. At these meetings, I described the purpose of the study, the ways in which I wanted their help with the project, and I solicited cases which the workers identified as problematic. Each meeting was followed up with personal memos to social work staff and a note of thanks to the director (see appendix 3).

Besides contact with social workers at these formal meetings, I

was familiar with department workers because of my association with the SCS. Individual workers attended rounds when they had patients followed by the service, so they were familiar with me from these meetings. When I encountered social workers in the hospital, I also attempted to engage them in informal conversation. Many workers were curious about my situation and asked questions about my research interests. I built on these relationships to encourage workers to be involved with the project and to suggest cases.

The structured opportunities for informing social work staff formalized access and insured administrative support for the project. In addition, two memos were sent at intervals during the data collection phase of the project (Appendix 3) to encourage and maintain participation. While the social workers were generally cooperative, residual suspicion from line social workers about their administration may have resulted in reluctance on the part of certain workers to participate in the study. According to some social work staff members, my friendly relationship with both old and new Directors of Social Service raised staff suspicions about misuses of interview material. Although I made special efforts to build informal ties with line workers, I encountered considerable variation in the willingness of individual workers to participate in the project. For example, two workers suggested multiple cases, while two others were reluctant to suggest cases. I was able to gain their cooperation only after numerous efforts.

The Department of Nursing presented the most barriers for approval for their staff participation and provided the most bureaucratic obstacles to the study. Initially, the SCS nurse coordinator suggested that I proceed without formal discussion with the nursing administration because she anticipated they would require a complicated approval process and delay the study. But head nurses expressed concerns about securing their administration's support, particularly since this study began during a period of stringent reporting of time utilization for staff nurses. Head nurses felt that any undocumented time would generate problems for them with their administration. Given my good relationships with the head nurses, I attributed their concerns to the developing strains between the nurses working on the floors and their administration. Also, since administrative constraint was a persistent theme in their formal responses, their concerns were probably not due to their reluctance to have their staff participate in the study.

After meeting with the head of the Medical and Surgical Nursing Department, I submitted a memo describing the project (see Appendix 2). Eventually, the project was approved by the Director of the Nursing Department. To obtain the eight hours of nursing time -- spread out over fifteen medical floors and six months -- which I requested required two one hour meetings with the department head, several phone conversations, and review time for the Director of

Nursing to pass on the project. This appeared to reflect extreme bureaucratization of the department, particularly since my work was under the aegis of two powerful physicians in the hospital, which made their denial of access improbable. Additionally, the extensive review process could have been an effort on the part of the Nursing Administration to show autonomy in decision making.

My case-finding efforts with the nursing staff involved personal contact rather than staff meetings, which were not available to me. My relationships with the head nurses were established in my work with the SCS and my identification with the nurse-coordinator of the service. As a clinical specialist, this experienced nurse was an actively utilized resource for the head nurses and their staff. Since we made rounds together each day on SCS patients, we were identified as colleagues, and her status gave me credibility with nursing staff. I approached the ten head nurses on the medical and surgical services individually, described the study, and asked for their participation. These ten head nurses presented the project to their staff during their own meetings. In two instances, head nurses suggested patients for the study. Head nurses and their staff were enthusiastic supporters of this project, no nurse refused to be interviewed when asked, and in three cases, they followed up their interviews with phone calls to me with further comments about patients, usually updates of their situations. Nursing informants for this study were universally

aware of the institutional constraints on their work. While head nurses were best able to identify these constraints, staff nurses provided good concrete examples of the relationship of their work to the administrative initiatives to hold the line on nursing costs.

Involving Physician Participation

Locating physicians-in-training to suggest study patients proved more problematic due to the rotation schedule, the exceptional demands on house staff time, and the lack of an accessible administrative format for reaching these young doctors. Because I was very familiar with house staff from teaching rounds and SCS activities, I was able to informally ask doctors I knew about suggestions for study patients, although this process was much less systematic and productive than attracting cases through nursing or social work. In spite of this gap, two physicians suggested cases as potential patients for this study.

The environment of a teaching hospital is accepting of scholarly research, since the culture of academic medicine is entrenched in scientific production through clinical and biomedical research. While this study was atypical in this setting in its methodology, discipline, and study population, conducting research in this setting was not. As a result, I was never required to

rationalize my efforts beyond the approval process. I obtained cooperation from individual staff. Any resources I needed for the project were available, including use of the rapid Xerox machine in the Department of Nursing.

Data Collection

Observations

Shortly after I accepted employment at EEH-IUMC, I began to keep logged field notes of observations and conversations which occurred during the course of my work. The initial entries in this log were unfocused, and I had no routine for entering observations. These entries included notes on possible dissertation topics. Once the project was defined and accepted by the dissertation committee, my field notes were more formalized and focused. From this point, entries were limited to staff interactions, conversations with professionals, and my observations of work with terminally ill patients.

Entries were based on a number of opportunities I had to observe the workings of the hospital in relation to dying patients. These included formal teaching rounds and SCS rounds to visit patients and to discuss them in interdisciplinary meetings; formal and informal interactions with individual professionals;

social events held by the division or SCS; observations made in hospital corridors and elevators and in the SCS and division offices; and staff behavior observed while visiting SCS patients. Table 1 presents the weekly meeting and rounds schedule I followed during the period of the study. I did not have a routine time for recording observations; rather, when an interesting event occurred, I noted it in narrative form in the log book at the end of the work day.

Focused Interviews and Chart Reviews

In addition to logged observations of the SCS patients seen during the course of my first year with the service, I wanted to interview health workers about "problematic" metastatic cancer patients in their practice. I planned to have either a nurse, social worker, or physician identify a "difficult" patient. After interviewing the professional who suggested the problem patient, I would seek out informants who knew the patient from the other two professional groups. Using this triangulated format I hoped to generate comparative data on the nature of problem patients for different disciplines. I anticipated that a sample of fifteen patients would be sufficient and planned to have eight medical social workers suggest at least one patient, and to obtain the rest

Table 1

WEEKLY MEETING SCHEDULE FOR CLINICAL PHARMACOLOGY AND SUPPORTIVE CARE SERVICES

Monday	Tuesday	Wednesday	Thursday	Friday
10 a.m. SCS Patient Rounds	9:30 a.m. SCS Discussion Rounds	10 a.m. SCS Patient Rounds	10 a.m. SCS Patient Rounds	10 a.m. SCS Patient Rounds
	11 a.m. SCS Patient Rounds			
	1 p.m. Clinical Pharmacology/ SCS Teaching Rounds		1 p.m. Clinical Pharmacology/ SCS Teaching Rounds	12:30 p.m. Clinical Pharmacology Research Update

from nurses and house staff.

While my initial plan limited the study population to problematic metastatic cancer patients, in keeping with the reformulative nature of theoretical sampling, I subsequently included AIDS patients. I also specifically sought out interviews with health personnel about patients who had remarkable remissions, since these patients seemed to represent an "ideal" patient type. These additions to the protocol enabled me to develop comparison groups of patients, in addition to the initially planned professional comparison groups.

Table 2 summarizes the number of interviews conducted and the sources of referrals for patients suggested for this study, along with patient diagnosis, private or pavilion service, and patient age.

The data collection for this project also included a chart review and focused interviews with health professionals. For both the chart review and the focused interview format, I developed a series of concepts from the existing sociological literature on terminal care. These concepts formed the basis for a typology which served as a framework during the initial stages of this project. Table 3 lists the concepts, their sources in the literature, and indicators which define them in practice.

The charts of all patients seen by the SCS were systematically reviewed from the time I began my employment until I obtained final

Table 2

DIAGNOSIS, SEX, AGE, AND REFERRAL SOURCE OF STUDY PATIENTS

Patient No.	Diagnosis	Sex	Age	Source of Original Referral
1	Adenocarcinoma of the lung	M	63	Nurse
2	Metastatic colon cancer	F	35	Social Worker
3	Leukemia	M	84	Social Worker
4	Breast?/Ovarian? cancer	F	73	Doctor
5	Ovarian cancer	F	68	Social Worker, Head Nurse
6	Metastatic breast cancer	F	49	Social Worker
7	Cancer of the penis	M	29	Social Worker
8	Lung Cancer	F	60	Social Worker
9	Brain Metastases	M	72	Social Worker
10	AIDS, PCP	M	42	Social Worker
11	AIDS, cryptococcal menningitis	M	51	Nurse, Social Worker
12	AIDS	M	27	Social Worker
13	AIDS, PCP	M	32	Nurse, Social Worker
14	AIDS	M	42	Doctor
15	AIDS	M	40	Social Worker, Head Nurse

Table 3

WORKING TYPOLOGY OF INDICATORS ILLUSTRATING TYPES OF PROBLEMS WITH DYING PATIENTS

Toxic Patients

Staff sees patient or family as:

asking too many questions
asking too few questions
asking professionally embarrassing questions
having delayed medical help
refusing promoted procedures or therapies
questioning health worker competence
demonstrating little confidence in health care workers
physically repugnant
exaggerating symptom intensity
underestimating symptom intensity
poor, inaccurate or inconsistent reporter
unwilling to delegate care to professionals when near death
unable to uphold denial
grieving openly
complaining
bargaining
expressing anger

Failure of the Acute Care System

Disease unresponsive to curative therapies
Doctors overzealous in pursuit of cure in hopeless case
Patient of little educational interest for medical training
Patient does not require sophisticated medical technology
Doctors turn over greater portions of patient management to nonmedical personnel
Attendings turn over greater portions of patient management to house staff
Doctors decrease time and frequency of patient visits
Supportive Care Service referral
Sick and dying role confusion

Table 3 continued

Social Death

Disengagement behaviors by staff such as:

- avoiding references to the future with patient
- placing patient in isolated area of the floor or on special floor
- excluding patient from future planning
- decreased patient contact
- DNR indicated on chart
- opinion informally expressed that patient should be support only, floor code or DNR
- suggestions of denial of active intervention
- actual denial of medical intervention

Disengagement behaviors by family such as:

- diminished visiting or phoning patient
- avoiding references to the future with patient
- behaviors as if patient is already dead, i.e., grieving, planning autopsy, disposing of personal effects, announcing contents of will, transfer of property, planning remarriage

Disengagement behaviors by patient such as:

- requesting limited visiting
- avoiding discussion of the future
- requesting limitations on active medical intervention

Death Trajectory

- Uncertainty as to time and shape of dying process
- Time and shape of dying process incongruent with deaths expected on a given service
- Time of dying process unexpectedly rapid
- Time of dying process unexpectedly protracted
- Dying process which interferes with work order of a given service
- Dying process which interferes with the sentimental order of a given service

approval from my doctoral committee to study methods. From January 1, 1984 through December 31, 1985, forty-seven metastatic cancer patients were referred to the service. Of these patients, thirty-eight charts were available for review. I limited the period of review to the time the patients were followed by the service. I developed a data collection form (see Appendix 4) for the chart review to organize the material by professional source and concept indicator. Social work, medical, and nursing notes were reviewed and conceptual indicators were recorded.

The Questionnaire

The focused interview format was based on the Typology of Concept Indicators and it contained a proposed range of problem types for the respondent to consider in relation to the patient. This format was an effort to cast as wide a net as possible for heath worker responses, but with some reference to the existing literature. The questions are broad in scope and required considerable follow-up and probing. The format provided a rough outline for the direction of the interview and, since it was applied to all three professional groups studied, it served as a good basis to compare responses.

The questionnaire (see Appendix 5) begins with an introduction of the investigator and a description of the project. It also

includes assurances of confidentiality of the responses and requests verbal permission to tape record the interview. The initial questions in the interview cover the informant's experience in health care and positive and negative aspects of the present work situation. The questions then address the specific problem patient, again with general questions about the worker's experience with the patient funneling down to specific examples of problematic or emblematic behavior. Probes for these questions were used to generate illustrative examples or to stimulate comparative examples from other experiences with dying patients. Since only the initial referral identified the patient as problematic, the informant is asked to comment on whether the patient is typical or atypical. Finally, the format reviews the list of problem types from the typology to discern whether any of these concepts applied to the particular patient's situation. If the informant was the professional who suggested the patient, s/he was asked to suggest medical personnel from the other two disciplines who knew the patient and might be interviewed.

The original interview format was pre-tested with a staff nurse on the surgical floor, a doctor who was a fellow in clinical pharmacology, and a pediatric social worker. None of these were included in the study sample. With each, I asked for an example of a problematic terminally ill patient in their practice. The case they identified became the basis for the pre-test. I also asked

them to comment on the format and make suggestions to me about its improvement as well as pointing out the presence of unclear, ambiguous, or leading questions. No changes were suggested and the interview time for the pre-tests ranged from thirty to seventy-five minutes.

Data Analysis and Feedback

After the first six interviews were conducted, I began an ongoing process of data analysis and feedback, this continued through the end of study period. I listened to all the recorded interviews twice and then wrote out by hand illustrative segments from the interviews on 5x8 index cards, noting the patient by number and the informant's initials and profession on the upper left hand corner of the card. At the same time, I began to review the log of field notes and similarly noted illustrative examples on 5x8 index cards.

When these initial data were distilled in this manner, I began to discern significant themes in the material which I then followed up in the next series of interviews. Specifically, at this point, repeated references to problems with AIDS patients and a specific request by an informant to include AIDS, led me to search out appropriate AIDS patients for inclusion in the study. I also began to log incidents involving AIDS patients. After noting several

times in the log that cancer patients with miraculous remissions were discussed repeatedly in SCS rounds, I began to develop the concept that "remarkable remissions" might indicate an ideal terminally ill patient type. This process of suggestion and reformulation continued until the construction of the typology presented in the next chapter, with several efforts at conceptualizing the data revised and rejected as new data emerged.

Conclusion

In this chapter I have presented the methods used in this qualitative study of the responses of health professionals to their work with terminally ill patients. I have described the advantages of qualitative methodologies for both the complex medical setting and the type of knowledge I sought to develop with this project. The specific methodological underpinnings for this study are well-established; they are described by Glaser and Strauss as "grounded theory" (Glaser and Strauss 1967). Particularly because of the reformulative process these authors advocate, theoretical sampling enabled the flexible integration of new concepts from the field to develop a fresh theoretical approach to problems in terminal care.

Next, I discussed the advantages and disadvantages of my position in the institution to conduct a participant observation

and interview study. While I had only limited problems in access, my caretaker role with the SCS presented problems in bias and overidentification with the study population.

Finally, I described the process of obtaining institutional permission to proceed with this study and efforts used to attract cases for the study process. The chapter also included practical detail regarding the construction of a focused interview format, chart review, and the systematic recording and coding of extensive field data.

CHAPTER FOUR

IDEAL, ROUTINE, AND "TOXIC" PATIENTS: PATIENT TYPES IN TERMINAL CARE

Introduction

Freidson (1973) has observed that in informal interactions, physicians spend considerable time discussing problem patients. Most of the work of doctors, nurses, and social workers concerns routine problems with routine solutions. Ordinary events proceed with little comment from caregivers. But though extraordinary patients — either extraordinarily good or extraordinarily bad — are the exceptional ones in hospital practice, they are a preoccupation for the staff directly involved with patient care. Hospital staff symbolize their work through exceptional patients to an extent that is disproportionate to their numbers or to the time required for their care; in some cases, the time required for care may be what makes the patient extraordinary (Freidson 1973). Following the parochial concerns of doctors, nurses, and social workers as they themselves define the exceptional in their practices can uncover significant issues in their work lives.

This study of the responses of health professionals to work with terminally ill patients focused on the way in which workers defined exceptional patients in this specific category. Bringing a structural perspective to health workers' definition of "good" and "bad" dying patients, I hoped to uncover some of the elements that defined these categories for health workers; not simply the patients' characteristics, but also the context in which patients were cared for and the expectations of health professionals for their work.

This chapter presents an original typology for "toxic," "routine," and "ideal" terminally ill patient types. The typology is the basis for analyzing the observational and interview data collected in this study and will be used as the basic conceptualization for the two subsequent chapters which discuss how health workers categorize terminally ill metastatic cancer patients and AIDS patients. The literature which discusses both medical and sociological perspectives on "good" and "bad" patients is included as background for this original typology.

Good and Bad Patient Types: A Review of the Literature

In formal transactions, health professionals use diagnostic labels to identify what is wrong with a patient. Diagnostic categories can have social control functions, such as described by

Szasz (1956) and other theorists. Nonetheless, within the confines of hospital life, where professionals go about the tasks of the day, diagnoses are a basic language through which professionals communicate about their work. These categories are defined through a process of differentiation which excludes possible explanations for a patient's symptoms until a diagnosis is reached. The diagnosis sets the stage for discussion of therapeutic interventions. Diagnostic labels of patients enable health workers to communicate about them in uniform and consistent ways.

Diagnostic categories are generally accepted and understood by staff. They are a part of the cultural language of doctors, nurses, and social workers in these settings. Often reduced to shorthand forms, such as "CA" for carcinoma, the diagnosis projects an image for the staff of the anticipated course of the illness. These images convey expectations on the part of the professional about the course of the disease, and what tasks will be required for patient care over time.

"Problem" patient labels are different from diagnostic labels in several ways. First, since a patient can only be a "problem" in relation to something else, usually the staff, labeling problem patients reflects judgments about what others think is appropriate behavior in a hospital. In that sense, "problem" designations do not have to originate in physical symptoms or patient complaints, but can be social evaluations. Second, while formal diagnostic

categories for problem patient types do exist in both psychiatric jargon -- for example "hypochondriasis" or "depressive equivalent," and the medical jargon, such as "Munchausen's Syndrome" they are not as distinct or universal as physical diagnosis. Terms to describe these patients frequently overlap in definition. Many different terms exist which describe the same behavior.

Efforts to formalize these distinctions in psychiatric nomenclature were undertaken in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) (1980). Presented in this context as disorders where the sick role is predominant, these definitions rely heavily on the secondary gain to the patient in being sick. These classifications include: somatization disorder, psycalgia, hypochondriasis, conversion disorder, factitous disorders, malingering, and undiagnosed primary disease. (American Psychiatric Association 1980) While physical symptoms may not be evident in these disorders, the frequency with which these patients collide with the medical care institutions increases the prospect for iatrogenesis, often producing problems which require medical intervention.

In sum, "problem" patient labels and diagnostic labels differ in two respects: they are social evaluations, and they are not as universal or discrete as physicial diagnoses. Beyond these two striking differences many of the terms used to describe problem

patients are crude and clearly meant only for informal conversations among professionals. Terms such as "gomer," "turkey," "gork," or "crock" to describe problem cases are unique to this issue. By contrast, "breast cancer" or "malignant melanoma" do not have equivalent informal labels.

Within the medical subculture, as part of the "backstage" behavior (Goffman 1961) of hospital life, informal labels are a distinct and characteristic way health professionals communicate with each other about difficult patients. As a result of the popularity of Shem's The House of God (1978), a fictionalized account of the closed world of house staff life, these terms have become familiar to the wider community. These labels communicate expectations and norms about good and problem patients as health workers define them, so that observing the context in which they are used can reveal their significance. The unattractiveness of these labels conveys the disdain of staff for difficult patients and the intense level of feeling they can evoke, especially in light of the normative expectations for discreet and considerate behavior among hospital professionals. They project the stress and conflict which surround the care of these patients. In the review which follows, I will discuss both the medical and sociological literature which explores "problem" patients.

Medical Views of Problem Patients

According to Reis et al, "the modern medical model seeks to identify specific disease entities, order accurate diagnostic tests, and give circumscribed treatments in order to 'cure' disease" (Reis et al., 1981, 257). These goals are frustrated in the case of difficult patients whose problematic behavior cannot always be attributed to physical disease. The response of these authors is to conceptualize different patient types according to diagnostic categories and develop proscriptive strategies for managing the problem. This article is typical of the analysis of medicine and nursing; they attempt to organize "problem" cases into specific categories and then suggest interventions for managing the patient. The "treatment" most often involves strategies which may not cure the patient, but may make the situation more bearable for the caregivers. The approach of Reis et al. is to use the DSM-III categories as the basis for differential diagnosis. They describe the characteristics of somatization disorder and hypochondriasis, among others, and their course and management (Reis et al. 1981).

Along similar lines, Drossman (1978) enumerates a series of differentiated categories for medical patients with psychosocial disturbances. These include "personalized or bizarre description of the symptom," "persistence of the symptom despite allegedly

specific medical treatment," as well as "the pain-prone patient" or "hypochondriasis" (Drossman 1978). In response, this author suggests a series of ten management techniques for work with these problem patients, among them to accept the symptoms and to maintain an unbiased interest. The physician is admonished to schedule regular visits and to be aware of personal attitudes (Drossman 1978).

Using a less formal construction, Groves (1978) describes "hateful" patients as those patients whom physicians dread. His categories, or stereotypes, include dependent clingers, entitled demanders, manipulative help-rejecters, and self-destructive deniers (Groves 1978). Lipsett (1970) describes the medical and psychological characteristics of the "crock" as a difficult patient type. Noting that doctors feel that chronic abusers of medical care are always present, even though their actual numbers are few, this author describes "crocks" as peripatetic individuals who use the hospital clinic as others use their home base. The former appear to be refractory to treatment. The persistence of such patients' desire to be cared for is described as a manifestation of depression, and the strategies with which Lipsett responds work with, rather than against, the masochistic depression manifested by "crocks" (Groves 1978).

Some medical descriptions of problem patients focus on a particular patient population; for example, the older patient

(Laurence 1986) or, of particular interest to this study, the dying patient (Levinson 1975). In an article describing management of the difficult dying patient, Levinson (1975) considers the impact of psychosocial variables on the care of terminally ill patients. This author puts the issue of terminal care in an historical perspective, which describes the positive impact of the death awareness movement on socially advantaged groups. Patients with psychopathology or who are from lower socioeconomic groups have not benefited from improvements in terminal care because of negative institutional attitudes towards less interesting or less deserving patients (Levinson 1975).

The medical literature reflects the tendency of the health professions to locate the source of the problem in the patient and fails to include the interactive or "countertransferential" issues in describing the problem. The sociological literature, however, confirms the social basis of problem patient definition by including both the contextual and professional expectations for good patient behavior.

Sociological Perspectives on the "Bad" Patient

The sociological literature on problem patients addresses the functions of informal labeling and attempts to tease out what these labels reflect the way health professions define their work.

This literature explores the contextual and interactive aspects of patient care as expressed through this language.

Several studies have examined the labeling process, developing categories of good and bad patients, as well as examining the relationship of these designations to the work expectations of health care personnel. Jeffrey (1979), for example, described the distinction between good and bad patients in English casualty departments. The good patients were interesting to the casualty officer physician and challenged the competence of the medical staff. Bad patients, known as "rubbish," presented trivial complaints. Drunks, overdoses, and tramps were considered bad patients and all were treated with disdain by staff. An interesting observation in this study is the fact that while good patients were described in terms of their illness, bad patients were described in social terms (Jeffrey 1979).

In 1975, Lorber studied the relationship between conforming or deviant behavior on the part of surgical patients, and their identification as good or problem patients by nurses and doctors (Lorber 1975). The willingness of patients to be obedient and accept hospital routines was proposed as a predictor of "good" patients. Yet analysis of patient evaluations suggested that ease of management was the most important factor for doctors and nurses labeling patients "good." Problem patients, on the other hand, were those whose care required more time and attention than staff

thought was warranted by the seriousness of their illness. Demanding behavior was perceived as problematic; however, patients who were unable to make their needs known to staff also required extra time to care for. The routine and usual were viewed as more positive than the uncommon, and this designation included routine and expected problems. When patients whose illness could be expected to be problematic were exceptionally cooperative or stoical, their evaluation by the staff improved. Problem patients were problematic because their behavior was difficult to manage or because their illness was complex (Lorber 1975).

As part of her study of the socialization of house officers to the doctor-patient relationship, Mizrahi (1986) described three categories of patients which house staff identified as undesirable. Self-abusers were those patients whose illnesses were seen as self-inflicted; system-abusers were the malingerers or manipulators whose complaints earned them the label "crock;" and house-staff abusers were ungrateful and hostile to the young doctors (Mizrahi 1986). In Mizrahi's setting, the profusion of undesirable patients had consequences for the labeling process as well as for patient care. Since so many patients possessed undesirable attributes, the best patients were those who could be quickly moved through the system, or "GROPed," an acronym for "get rid of patients" in this author's terms. Eighty percent of the house staff admitted that a negative label affected the social and

medical treatment such patients received (Mizrahi 1986).

Most recently, Liederman and Grisso (1985) analyzed the characteristics of patients labeled "gomers" by medical house staff. The term "gomer" is thought to be an acronym for "get out of my emergency room." Again, social indicators were more predictive of negative labeling than medical ones, so that gomers were no more ill than control patients in this study. Rather, the problems of the gomer patients were frustrating, engendered disagreement, and aroused uncertainties among the house officers caring for them. These difficult patients suffered more mental decline, presented difficult diagnostic and therapeutic and ultimately disposition problems. For these authors, the "gomer" represents the inability of the medical system to care for socially isolated patients and those whose illness cannot be resolved within the confines of the present technological system (Liederman and Grisso 1985).

The original typology of patient types which follows is based on observations and interviews with EEH staff about their work with terminally ill patients, both metastatic cancer patients and patients with AIDS. While previous studies of patient labeling have focused primarily on physicians and, to a lesser extent, nurses this model was drawn from the three professional groups included in this study, allowing for comparisons among the three groups.

A Typology of Patient Types and Health Professional Needs: "Toxic", Routine, and Ideal Terminally Ill Patients

Health professionals working in complex acute care hospitals generally evaluate patients as "good," "average," or "problem" according to three variables. First, nurses, doctors, and social workers want the interventions they employ to cure the disease or ameliorate symptoms. They expect to perform their work through established and orderly routines. Finally, all professional groups would like personal gratification from their work. These three variables constitute ideal expectations for the expressive and institutional rewards professionals anticipate from hospital practice. The extent to which these expectations are met by individual cases determines whether the health worker evaluates the patient as "good," "average," or "problem."

In the typology presented in Table 4, I use labels to describe terminally ill patient types which represent usage in the setting of the study. Patients are either "toxic," "routine," or "ideal" in relation to the professionals' needs for cure or symptom amelioration, routinized work, and personal gratification. These designations imply the degree to which professional and institutional expectations are met by patient behavior, response, and illness characteristics. The process is interactive, and the factors are interrelated, so that the resulting patient label is a product of professional needs and patient behavior and responses as

Table 4

TYPOLOGY OF TERMINALLY ILL PATIENT TYPES:
IDEAL, ROUTINE AND TOXIC PATIENTS

Worker Needs

	Effective Intervention	Work Routines	Personal Gratification
IDEAL	Remission	Highly Cooperative	Expresses Gratitude
ROUTINE	Amelioration of Symptoms	Moderately Cooperative	Emotional Neutrality
TOXIC	Poor or No Response	Obstructive	Hostility

they play off each other over the course of the hospitalization. Labels can be reinforced or neutralized, or they can change over time as the illness develops and circumstances in its treatment change.

In this schema, the patient categorized as "ideal" exceeds health professionals' expectations for work with dying patients. These patients respond beyond expectations to treatment. Whether or not the outcome can actually be attributed to the medical intervention, this highly prized patient group is identified as "ideal." Ideal patients also have personal characteristics which engage the altruistic motivations of health professionals, such as heroically accepting pain or uniquely expressing gratitude for care. Ideal patients present minor caretaking problems. Of course, the better the results, the more patients appear heroic and grateful, and the more staff are willing to accommodate caretaking problems. Health professionals often spend more time visiting with and discussing ideal patients than other patient types. This also reinforces good patient response, both behavioral and physical.

An example of the ideal patient, Mrs. B was a 67-year old woman with metastatic ovarian cancer. She was followed for two years by the SCS, both in the hospital and later at home when she was enrolled in an accredited, Medicare certified hospice home-care program. Originally referred for a pain control consultation, Mrs. B. was initially unresponsive to the usual interventions. Finally

the team developed a good pain control regime which ameliorated her distress. After her third hospitalization, Mrs. B. was sent home "to die" under the care of a hospice program. Mrs. B. survived eighteen months past the discharge date. Under the eligibility requirements for Medicare hospice programs, Mrs. B.'s prognosis was a life expectancy of less than six months. During the time when Mrs. B. was at home, the SCS medical director assumed management of her pain. He visited her weekly on his way to the hospital in the morning and took a series of medical students and house officers to her home to show them the results of high quality terminal care. As the patient improved, she left her house in a wheelchair in good weather and took two trips to her daughter's beach house. The medical director was also invited to the beach house, where he spent a weekend with his wife.

Mrs. B. was frequently discussed in SCS rounds, even though her situation was stable and her narcotic and laxative medications remained unchanged. Both Mrs. B. and the medical director attributed her extended life span to the excellent home care and the personal attention she received. Mrs. B. enhanced her ideal status by repeated expressions of gratitude, easily made in the context of her improved condition. Her frequent comment to the medical director was, "You're the one who is making this happen."

Mrs. B. was the prototypic "ideal" dying patient. Her outliving her life expectancy and her frequent reinforcement of the

efforts of professionals working on her behalf made the physician enthusiastic about her management. The routines for providing Mrs. B.'s care were simple for the doctor. Her home was located on his way to the hospital and the medication orders were straightforward and easy to administer and achieved good results. Their simplicity and stability limited problematic interactions with home care nurses who provided direct care. Finally, the patient was an attractive, upper middle-class woman, with whom the doctor could easily identify.

By contrast with ideal patients who exceed expectations, "routine" patients simply meet normative expectations. They have some amelioration of symptoms or problems and present average management problems for health professionals. These can be resolved by established or new, but easily negotiated, routines. For example, cancer which has metastasized to the bone can cause severe pain for terminally ill patients. As a result of the experience of the hospice movement and consequent research in chronic pain control (Tycross and Fairfield 1982), around-the-clock administration of narcotic medications has become an accepted regime for managing this common symptom. Not only does this routine ameliorate the symptom, it also reduces complaints of patients and family members and disruption of regular work routines. As long as these patients are emotionally subdued, staff members tend to be neutral in their interpersonal responses.

Consequently, these patients do not evoke significant staff affection or identification nor do they evoke negative reactions.

The "toxic" patient type is the most complex and difficult patient for staff to manage. The term "toxic" suggests the disruptive impact such patients have on hospital routines. The term originated among SCS staff to identify exceptionally problematic patients referred for complex pain management and psychosocial problems. It emphasizes the interactive nature of management of the problem patient within the hospital system and, in that sense, it is different from terms presented earlier, such as "gomer," or "health care abuser." These latter terms obscure the fact that medical staff define problem patients as such because they do not meet existing institutional and professional expectations.

"Toxic" patients generate conflicts between peers and colleagues and require unusual amounts of time and resources from staff. For example, certain patients do not respond to the usual narcotic regime for severe pain either because the source of the pain is nerve infiltration, typically not relieved by narcotics, or because they require greater than usual amounts of drug for adequate effect. Frustration and conflict develop as the patient and family persist in their complaints and staff members use conflicting ideologies and practices in grappling for a solution to the problem.

Some staff members may blame the patient for drug-seeking behavior as a way of explaining persistent requests for more narcotics. Others may advocate increasing the doses of the narcotics in an effort to solve the problem, or suggest other technologies, such as nerve blocks or narcotic infusions, such as morphine drips. Frequently, the medication charts kept on such patients show constant changes of drugs, doses, and dosing intervals, which defy all principles of rational therapeutics. These problems can be compounded further if the disease process includes mental status changes such as short term memory loss. In these cases, patients may report different levels of pain to different health workers because their assessment is based on the immediate situation. The resulting confusion generates further staff conflict among nurses, house staff, and attending physicians.

Technical failure produces its own problems for management in situations where it is not that "nothing more can be done" but, rather, _what_ is done that can further confound the problem. Concerns about iatrogenesis develop, or therapeutic treatments do in fact produce their own complications. "Toxic" patients become a preoccupation of staff, generating a profusion of anger and frustration. These patients are a frequent topic of informal discussions and argument among those caring for them.

Certain disease characteristics are also indicators of patient toxicity. A striking example was a patient suggested for this

study who had the unusual diagnosis of cancer of the penis. On this basis alone, a social worker defined the patient as problematic because of the psychological impact on staff, particularly young male physicians-in-training. In spite of the patient's cooperativeness and "good" patient behavior, his disease generated enough anxiety on the part of the staff to place him in the "toxic" category.

Patients may come to be defined as "toxic" because they have personal characteristics which hospital staff find unattractive or repulsive. Even the best of patients may question professional authority, make demands, and voice complaints when they begin to deteriorate physically and mentally. An example of such a change in status, Mrs. F. was an attractive and lively 37-year old woman with metastatic breast cancer. She was followed by SCS for pain control. Initially, Mrs. F. was easy to manage and additionally engaged staff with her optimism and gratitude for the attention she received. Coincidentally, when Mrs. F. began to experience serious pain, she was moved to another floor. At this point, she was placed on a palliator, a pump device which enabled her to control her own administration of the narcotic drug, Dilaudid. However, her pain proved intractable in spite of the special device, and the presence of a new piece of equipment meant extra work for the nursing staff. The narcotic was in special vials which could be released only if a floor nurse went personally to the pharmacy to

sign them out. Also, the routine was complicated and unfamiliar, so that workers in the pharmacy were not always certain what was required for the drug's release. As a result, the palliator was not always filled with the drug, and the patient became anxious and complained frequently about the lack of medication. Even when the clinical fellow with SCS took over the responsibility from the floor nursing staff, the problems persisted. The house staff complained about the patient's demanding behavior and told the fellow they thought the patient was exaggerating her symptoms. The problems with Mrs. F. became further exacerbated when she began to develop mental status changes, attributed by house staff to excessive narcotic administration.

When patients are tractable, family members may not be. Patients may be identified as routine or ideal based on their own characteristics while the family's interactions with staff may produce inflammatory situations. As an example, a wife barred floor nurses and house officers from her husband's room at the same time she kept equipment in her room which was meant for the general use of the floor.

Illness Trajectory

Diseases and patient labels are not static. As described above, patients can move from one category to another as

their diseases progress and as new interventions are applied. Strauss et al, developed the notion of the illness trajectory to describe the dynamic process of illness management (Strauss et al. 1985). This concept includes the physiological progress of a patient's disease and the organization of work performed over the course of the disease, as well as its impact on the staff and the larger hospital organization. While these authors concede that the concept could be applied to most work contexts, they identify two elements which are special features of health work (Strauss et al. 1985). According to Strauss et al. health work is unique because of the unexpected and hard-to-control contingencies that stem not only from the progress of the illness, but also from multiple work, organizational, and patient sources. A special feature of health work in hospitals is that what is worked on are people who can react, participate in, and in turn shape the work. The above examples stress the importance of this feature of health work in professional labeling of good and problem patients (Strauss et al. 1985).

These authors identify two other sources of trajectory complexity that are particularly relevant in contemporary hospitals — the prevalence of chronic illness and the development of new treatment technologies. These factors are interrelated, since to some extent the production of new medical interventions has resulted in an increased number of patients with chronic disease

living longer. Diseases such as cancer or diabetes which in the past would have ended with acute episodes may now be protracted by new therapies. Thus, however welcome, new technologies upset preexisting routines. These technological changes reverberate along the illness trajectory and require integration in patient management. In addition, medical advances have produced resource allocation, ethical, and patient management problems which did not exist for past generations of health workers (Strauss et al. 1985).

Chemotherapeutic therapies for cancer are an apt example. The side effects of these treatments are often discomforting, disfiguring, or exhausting for patients. While the treatment can precipitate remission, quality of life may suffer. Because they can prolong the lives of patients, they have extended and reshaped the illness trajectory for many patients, binding them to health delivery systems.

Personal and Disease Characteristics: Forgiven and Unforgiven Patients

An extensive body of literature describes the objectification of hospitalized patients (Cartwright 1964, Goffman 1961, Lorber 1975 and Mizrahi 1986). Medical personnel, particularly during hospital training, have been observed to dispense with ordinary civilities such as social introduction, or to completely disregard the human qualities of patients. The form and style of these

interactions conveys an apparent preference among medical professionals for compliant, accepting, and submissive patients. Hospital professionals reinforce these behaviors through depersonalized interactions so they can get on with their work. Lorber's study of hospitalized surgical patients supported the theory that "good" patients, from the staff's point of view, are those who allow work routines to proceed undisturbed. They are cooperative and undemanding, yet inform staff enough to enable them to proceed with care. Patients who are too uncommunicative require extra work (Lorber 1975).

Because of the professional's need for routinized work, in the data collected for this dissertation health workers identified demanding behavior, self-inflicted health problems, delays in seeking medical care, refusal to accept recommended treatment, pursuit of unconventional therapies, or obstruction by family members as obstacles to work production. These professionals reported that the type of affective response from patients and their families also influenced their assessment. Expressions of gratitude, heroic behavior, physical attractiveness, or perceived ethnic or socioeconomic similarities to health professionals were frequently indicators of patient "goodness." Lorber, in fact, suggests this component of patient "goodness" with an illustration of a woman volunteer with Cancer Care who had cancer, who was cited by her nurses and doctor for her exceptional bravery (Lorber 1975).

These affective elements take on considerable importance, particularly with terminal illness which can generate complex work problems and treatment failure. Since the rewards of effective curative intervention are absent, little else is left to sustain a worker's commitment to often custodial support and distasteful tasks.

In spite of the predilection of health personnel to identify patients by their diseases, personal characteristics of patients are distinct from the manifestations of their illness, which also influence staff evaluations of patients. Certain diseases respond to well-established technical interventions, the classic example being antibiotics for infection. The effects of most technologies are far less sure. Specific diseases and symptoms can evoke negative reactions among health workers. Some illnesses demand complex care regimens, which create additional work for nurses, doctors, or social workers. As I will illustrate later, failed technologies can precipitate disruption in established work routines with cancer and AIDS patients.

The importance in distinguishing "toxic" dimensions as patient or illness characteristics lies in the way health professionals use these characteristics in assigning or not assigning blame, and consequently, whether the patient's "toxic" status is or is not forgiven. Daniel Fox observed that since the 1970's, with evidence that changes in personal behavior could be effective in preventing

and controlling illness, patients are supposed to take individual responsibility for their health status (Fox 1986).

Life-styles, such as dangerous homosexual practices associated with AIDS or cigarette smoking associated with lung cancer, demanding or obstructive behavior, noncompliance, or pursuing non-traditional therapies are patient-generated behaviors for which the patient and family are held accountable. And, patients with terminal illnesses are most inclined to be demanding and to seek unconventional forms of treatment. These negative patient behaviors are not forgiven in patients evaluated as "toxic."

In contrast, illness characteristics which health professionals conceptualize as symptoms of the disease are forgiven by staff even if they create work problems. This is especially true if the patient expresses extreme gratitude for care. When patients are emotionally neutral, their disruptive disease characteristics usually lead to an evaluation of "routine." When the patient's behavior is problematic and the disease characteristics are disruptive, the case is "toxic." Even this label, however, is subject to change under the right conditions. An interesting example of a "toxic" patient who moved from unforgiven to forgiven status was reported to me about an AIDS patient. His demanding behavior was initially seen as a personality characteristic. When information about AIDS encephalopathy developed and the problem was attributed to short-term memory loss, his behavior was forgiven.

He was now a "routine" AIDS patient who was no longer culpable for his demanding behavior.

AIDS patients may appear to have so many toxic characteristics that the label "toxic" can be said to be "overdetermined." AIDS is clearly a "toxic" illness because of its inevitable fatality, the stigma attached to homosexuals and IV drug users who presently form the majority of affected persons with AIDS, and the fact that health workers are concerned about contracting an inevitably fatal illness in caring for these patients. Yet some AIDS patients are described as "innocent victims," both by staff and the media. Pediatric patients and hemophiliacs, and to a lesser extent sexual partners of infected bisexual men or IV drug users, are not held morally accountable for having contracted the disease. Homosexuals and IV drug users, on the other hand, are frequently blamed by staff for having engaged in unsavory or possibly immoral personal behaviors which put them at risk for contracting this illness.

Additionally, health workers observe that some patients appear to overcome the "toxic" status generally assigned AIDS patients. In the words of a social worker regarding her AIDS patients, "some patients charm the givers of care." Affective rewards for staff through expressions of gratitude or affection are profoundly important to hospital workers, as they represent the final validation of their efforts -- particularly where few other rewards

exist. AIDS patients, like other terminally ill patients, can engage care providers with their personalities. In cases where patients or family members exhibit heroic behavior, patients may be assigned "ideal" status, as exemplified by aging parents of an AIDS patient who moved into their son's room and provided hands-on terminal care for their child until his death in-hospital. A nurse's comment that "they weren't even afraid of catching the disease" confirms not only the attribute of dedication on the part of the family but also the highly valued quality of heroism in their behavior.

Conclusion

In this chapter I have presented a typology of ideal, routine, and "toxic" terminally ill patients. The typology was drawn from observations and interviews with doctors, nurses, and social workers about their work with dying patients. Ideal patients exceed health worker's expectations for their treatment or have personal characteristics which are prized. Routine patients are those who meet normative expectations. "Toxic" patients disrupt hospital routines or have unattractive personal characteristics.

These labels result from the interaction of professional expectations and patient responses and behavior as they develop over time, so that the labels are not static. Patients are blamed

for their bad behavior when they are seen as responsible, but when their "toxic" status is construed as a manifestation of their illness, they are forgiven. In the chapters which follow, these concepts will be used to describe how health workers categorize their terminally ill patients.

CHAPTER FIVE

"TOXIC" DIMENSIONS: TERMINALLY ILL CANCER PATIENTS

Introduction

Terminally ill patients do not respond to curative interventions. At this point, health professionals must exchange their expectations for cure to the comfort work of palliative and supportive care or to planning for terminal care. For medical personnel working on hospital medical units, work with terminally ill patients produces few professional and institutional rewards and can undermine the very sources of personal achievement that motivated them to enter the health field. These cases produce a reservoir of stress and failure in the midst of the technical advances which excite and falsely stimulate a sense of power over patients' lives. The conflicting interests and work constraints of professionals in modern acute care hospitals make terminal cases problematic, yet health professionals rarely receive institutional or peer support in these hospitals when they experience the emotional stress of working with dying patients. Thus, by the very nature of their disease status, terminally ill patients are difficult for professional hospital staff to accept psychologically

in acute care institutions.

While the growing prevalence of chronic illness in this country might dictate otherwise, the structure and mythology of general hospitals continue to depict them as a place to restore people to health (Strauss et al. 1985). When curative interventions are no longer effective, medical professionals may face a sense of personal uncertainty and failure and the insensitivity of organizations which do not respond to the needs of those in their care (Mauksch 1975). Moreover, since reimbursement requirements for acute care hospitals deny third-party payment when a terminally ill patient requires only comfort care, much of the work with patients who are no longer receiving active treatment is to arrange their discharge from the hospital.

Since dying patients represent failed interventions for conventional care givers, terminally ill patients are vulnerable to being labeled "bad" or "problem" patients. Yet, not all dying patients are identified as problematic by staff in acute care hospitals. Moreover, certain terminal cases are more problematic for some professional groups than for others. As aspects of comfort care or discharge planning become routine within the hospital, problems of terminal care may find solution, at least from the health worker's perspective.

Routines for the care of the dying have many sources. When pain control regimens that include around-the-clock administration

of narcotic drugs became accepted therapy for metastatic cancer patients, many pain control problems were resolved (Health and Policy Committee, American College of Physicians 1983). In fact, research which supported adequate narcotic administration for terminally ill patients developed from hospice work and shows how a specific and utilitarian care model from the hospice movement gained acceptance in traditional medical settings (Mount 1976).

This chapter reports on observations of terminal care by professional staff at EEH, a large, tertiary care teaching hospital, and uses vignettes from interviews with staff members about terminally ill metastatic cancer patients identified as "difficult" by doctors, nurses, and social workers. The next chapter will discuss the problems of health care workers with hospitalized AIDS patients.

I have analyzed the data according to the original typology presented in Chapter Four, which considers patient and illness characteristics within the context of a complex set of institutional dynamics. This chapter describes the way in which health professionals characterize "toxic" terminal patients and contrast them with routine and ideal terminal patients. These labels reflect interactions among patients and staff, the constraints of institutional life, and the responses of different professional groups in work with terminally ill patients.

Technological Impact: Death as Failure

The Dying Patient in The Tertiary Care Hospital

Although the three professional groups studied play very different roles in the process of patient recovery and discharge, the goals of curing patients and returning them to the community are the ultimate sources of reward for health personnel working in acute care hospitals. The interventions which different health professionals bring to this process are a function of the training and expertise of their respective disciplines. While the scope of professional activities of nursing and social work are broader than the cure of patients, these professional groups still operate in a system where the imagery of "success as cure" predominates, and their vision conforms to the medically dominant perception.

The fact that EEH is a tertiary care hospital may further complicate the problem of disparity between expectation and outcome, both for medical staff and patients. Patients are referred to this hospital because it offers expert and up-to-date medical care beyond what local doctors or specialists can provide. Therefore, many patients arrive with advanced disease, as well as a sense that they can be helped. According to a junior resident:

> We don't deal well with dying in this institution. Maybe it's the prestige of the institution or that people think it's the "mecca." Basically, they come here for a cure. The patients have this sort of expectation. And, certainly, it's partly our

> fault in situations where it's not warranted, giving false hope and false expectations of what's going to happen. It leads to frustration on everyone's part when they know things aren't going to go well and they have to deal with it.

The house officer's comments imply that both patients and staff internalize this ideology, so that consensus reinforces for each constituency a belief in the power of advanced medical technology available in the hospital.

Whether the source of this expectation is primarily the patient is arguable, since the hospital itself does much to augment its reputation for being in the forefront of medical science. For example, the glossy public relations monthly which is prominently displayed and available to hospitalized patients describes new equipment and technical advances available to patients. Maintaining the image of a hospital which is technically up-to-date is important for recruiting both new patients and institutional benefactors. The interactive aspirations of patients, staff, and the institution for cure supports the expectation of cure, even if it is often not really achievable.

An experienced head nurse on a private service confirmed the symbolic significance of curing patients:

> Even though they call this floor a "general medical floor," I see it as "oncology." Two-thirds of our patients have some sort of cancer or are having a cancer work-up. The only recent development is AIDS. We have a lot of patients with AIDS. We consider it a malignant disease. It seems we're always doing cancer. It has a great effect on staff. We have a big morale problem with nurses on these floors. That is, everyone wants

> to be successful and success means curing someone and sending them home with a bouquet of flowers, and they're laughing, and all their get-well cards are tied up in a little bundle. You get that satisfaction on a surgical unit. On a medical unit like this, a lot of people don't go home. A lot of people go home to die.

The comments of a senior resident mirror the head nurses' perceptions of the expectations of their staff:

> The most problematic thing for me is learning to deal with failure — when patients don't have a good outcome. We're geared up to sort of cure, or at least manage most illness. And when you don't do that, it's failure. It's a mind frame that you have that you're supposed to do 110% for everyone. When they don't get better, then something didn't work right. I'm probably expressing my disillusionment with internal medicine. It's a field where you don't cure a lot of people.

These responses capture the difference between the expectations these professionals have for their work and the limited opportunity in their work lives for actually achieving this ideal. The professionals offering these comments are referring to disease states which elude "cure." Many cancers and AIDS, along with any number of chronic conditions which make up the bulk of cases seen on inpatient medical services in this hospital, do not by their nature offer this ideal resolution. Yet doctors and nurses, particularly as they begin their clinical experience, anticipate the satisfactions of success by a specific definition of cure. Frequently, they continue to seek such satisfaction despite the experience of years of practice to the contrary.

"Toxic" Dimensions for House Staff

House staff must accommodate their emerging realism about what can actually be accomplished with terminally ill patients. As the senior resident who expressed his disillusion with internal medicine said:

> You tend to avoid failure. You also have twenty other patients who are critical and not doing well. It's just tough to deal with the situations. So you just stick with the medical management and don't try to deal with anything beyond that.

An intern, also recognizing her limited curative successes, was able to redefine the source of her rewards:

> Nobody wants to see somebody die. It's incredibly depressing. I can just tell you from when we walk around on rounds, there are certain patients who just look awful and feel awful, and you know there is nothing you can do for them, and you don't want to be with those patients. One of my first patients was a lady with metastatic breast cancer, with pleural effusions and shortness of breath. She was just very sad. My initial feeling was how frustrating it was. There was nothing I could do. I knew she was going to die. Somebody wise said to me, "All you can do for this lady is to be psychologically there for her, supportive of her. And you'll be surprised. You think you're not doing anything for her, but you really are." And with that kind of attitude, it made a tremendous difference.

For many terminally ill patients in acute care hospitals, alternative intervention means a shift from curative to palliative strategies. Correlative with this shift to "comfort care" is a

shift in staff allocation since the latter type of care is generally managed by nurses under physician supervision. A common example referred to earlier in this study is pain control. Many end-stage cancer patients require symptom management technologies which are not seen as requiring sophisticated skill or a physician's knowledge unless the pain is intractable and does not respond to the usual interventions. In these cases, ineffective interventions precipitate patient toxicity, as patients and family members respond with their own frustration to the helplessness of medical staff to control the symptom. Accepting the appropriateness of palliative intervention in end-stage disease, individual patients become "toxic" when even interventions offered for palliation prove unsuccessful. This structural accommodation to patient toxicity protects the most valued staff, i.e., physicians, from continuing exposure to these patients as they transfer responsibility to those lower on the prestige hierarchy.

"Toxic" Dimensions for Nurses

Nurses are the health professionals most intimately involved with patient care, so that many of the needs of terminally ill patients become their responsibility. In that sense, they are the recipients of many of the problem issues which failed patients represent; for example, intractable pain, family concerns, and

expressions of patient and family dissatisfaction with the ability of the medical system to cure the patient. Frequently, in fact, the problems which arise with terminal care patients come to the attention of the nurses first and have the greatest impact on their everyday work.

Young nurses come to their work with the same ideal expectations as house staff, and they must also come to terms with the realistic limitations of their efforts. For head nurses who are responsible for training new cohorts of recent nursing graduates, the process of acculturating the initiate nurse to the moribund realities of floor life is a constant process given the large turnover of staff nurses on medical floors. They must also contend with the disinterest of the nursing administration to recognize the special needs of medical as opposed to surgical services, where there is clearly much greater congruence between the desire for healthy outcomes and their probability. For nurses who must care for hopeless patients, the result is little institutional support in the form of in-service training or clinical specialists.

The head nurse quoted above redefined her service as an "oncology" service, expressing a particular commitment to cancer patients, as well as persistent advocacy for her staff nurses. She was able to exchange the idealized professional expectations for realistic and effective interventions that emphasized palliation

and psychosocial support. These care dimensions became the normative standard on her floor.

"Toxic" Dimensions for Social Workers

Effective interventions for social workers involve establishing therapeutic relationships with patients, advocating for patients in the hospital environment, and locating available community resources. When patients are terminally ill, social workers' interventions are necessarily focused on the obvious need for terminal care planning and psychosocial support. In fact, technical failures for medical staff can provide treatment opportunities for social workers. For example, social workers may observe when house staff and nurses are avoiding patients; they can offer those patients supportive intervention. In so doing, they do not challenge the appropriateness of nurse or physician behavior and do not attempt to pass the patient back up the status hierarchy. One senior social worker described her attentiveness to terminal cancer pain:

> Sometimes with dying patients, I would say it's "forgetfulness" rather than "insensitivity" about patients needs. Sometimes I feel more has to be done about making the patient's end bearable...I don't think enough is done to evaluate pain on a daily basis — to know from one day to the next if the medication is working. Sometimes I find myself asking a patient about his pain, and it's usually received OK — social workers should be advocates.

In contrast with doctors and nurses, social workers described how rewarding their work with spouses and other family members can be. For example, one social worker comments:

> I like seeing the patients and the family mostly. It seems that most of the patients don't survive the admissions now and the families have to go on...The patients on this service seem to be quite ill. I've had, in fact, two patients expire this weekend and the family members were in there on Monday to see me. That's the interesting thing. I've been working with them closely before anticipating the death. Generally it's the wives who come more often. They seem to be the ones running the household, not knowing what to do next. The two situations over the weekend, there was no one to turn to for the smallest piece of advice, a shoulder to cry on. That's what they used me for.

In such terminal cases, social workers can still be successful in giving initial assistance and both concrete and supportive bereavement counseling.

In the eyes of house staff and nurses, the discharge planning function of social work is an important if lowly function, primarily because it removes terminally ill patients from the floors. Or, as it is tellingly described in the local vernacular, "it keeps the drains open." Discharge planning functions for patients who are cured or improved engender greater optimism and enthusiasm than plans for the dying. Nonetheless, in the eyes of social workers, "toxic" patients are more likely a result of disrupted routines or limited resources than of failed intervention.

"Toxic" Patient Types

Patient and Family Involvement

While the disease state of patients is one obstacle to professional interventions, patients themselves as well as their family members can actively obstruct staff efforts. Erle (1982) puts terminally ill patients into two categories: "settlers" and "fighters." "Settlers," in his terms, are patients who accept the inevitability of fatal illness and are not interested in pursuing curative measures after a fatal prognosis. "Fighters," on the other hand, are patients who would pursue any curative intervention, even when the possibility for a successful outcome is minuscule (Erle 1982). At EEH, if medical personnel decided that a technology should be applied, they wanted patients to behave like "fighters." When patients would not embrace their technological offerings, they were defined as "toxic" by staff. Their resistant behavior could also set up conflicts among staff members who attached themselves to constituencies either for or against intervention, or when they manifested their fighting behavior by seeking nontraditional treatments. Frequently, conflicts extended past the physician/patient dyad and embroiled other staff members in interdisciplinary or collegial contests over individual case management. A social worker described a case where the house staff

wanted to treat a patient with advanced disease:

> (Head nurse) mentioned that the house staff was annoyed at the wife because they felt there was more that they could do. When that man came in, he was viable and they were angry at his wife because she wouldn't go ahead with ordering tests, so that he could be treated. Therefore, they were feeling anger directed towards her. I can't justify that — all I know is that this man has been sick for weeks here.

In this example, the family's desire to "settle" conflicted with the interventionist position of the house staff. Additionally, it reveals the reluctance of the social worker to challenge the situation as defined by medical personnel.

Interns and residents may advocate treatment if they perceive an educational value in intervention, since an important function of the training years is to expose young doctors to as much practice as possible. If they identify a case as "hopeless" but without educational value, on the other hand, they will object to an attending who wants to pursue treatment:

> I'd like to ask attendings not to approach families with false expectations, but it's tough to do. Sometimes the attending feels close to them and he is not going to take away their hope, even though scientifically there is no hope. Here you are, a resident, telling an attending who has had more experience than you how to take care of his patient.

Since house officers provide the body care for patients on their rotations, they often resent the burden of another physician's decisions. In such circumstances, they are placed in a position of defending the attending's perspective with a patient,

even when it is not their own.

Patients Who Reject Doctor's Recommendations

Patients become "toxic" when they or their family members reject interventions which doctors feel would be beneficial. Established doctors, as well as house staff, can also press for intervention against a family's desire. A social worker reported a case where an attending physician became angry when a patient's wife refused intervention. In response, the attending notified the Utilization Review (UR) nurse directly in an effort to facilitate the patient's discharge. The social worker who described the case was ultimately caught between the doctors and the family:

> I get a lot of calls from the residents and interns because they don't know what's going on with Mr. S. Because Dr. Y. put a note in a charge asking for the UR nurse to see them. Mrs. S. (patient's wife) had come in about a week ago and said that Dr. Y. had sat down and recommended an endoscopy. If it were done it would give them a definitive picture of what could be done with his treatment and case. But Mrs. S. refused it. She didn't cooperate with him by saying you can have this test. And she is very much of a person who is a factual person. She has been through her own cancer and seems to know the score. She had worked with a hospice program.

The social worker found the oncologists' actions "unusual" since she had never known an attending to advise a UR nurse directly of the need to have a patient discharged. Typically, UR nurses made their own discoveries through periodic chart reviews

and if attendings discussed discharge planning it would be through a direct referral to nursing and social service staff. The social worker felt the attending's actions were punitive. Notifying the UR nurse generated a series of letters from the Utilization Review department which stated that if the patient were no longer treated for acute illness, then the hospital could not claim third-party reimbursement and the patient and his family would be responsible for the expenses in the hospital.

Even though the patient was too ill to act on his own behalf, the Utilization Review form letters were delivered to his bedside, admonishing the patient to cooperate with social service in arranging his discharge from the hospital. When the wife approached the social worker with these letters, the worker was in the position of having to develop after-care plans with a hostile family member. Because the usual referral mechanism was circumvented, she was also uninformed about the patient's needs and circumstances. The wife felt her husband was too ill to be discharged and thought he belonged in the hospital, so she stalled the social worker on discharge plans:

> The intern and the resident keep calling me. They don't know what's going on. The doctor's notes say to refer to social work. I could do any kind of plan but she's just resisting it. She says he's dying and she's not moving him anywhere. My note wasn't clear — I wasn't clear. The wife was refusing to have plans made, yet Dr. S. was saying that plans had to be made. You know I can't send in any forms unless there is an agreement with a family member and I noted that in the chart.

The patient died before after-care plans could be arranged. This relieved the social worker, who found herself caught between the doctor's desire to treat his patient as he saw fit and the desire of the patient's wife to have her husband die peacefully in-hospital. EEH could not reasonably be expected to keep this patient in-house at its own expense. In fact, the patient might have received more appropriate terminal care elsewhere. Yet the wife's desire to "settle," on one hand, and the desire of the oncologist for aggressive intervention, on the other, generated a unique series of events which defined this patient as "toxic" for both the social worker and for medical staff. For the attending physician, the toxicity stemmed from the families' rejection of the proposed intervention; in other words, the wife interfered with his actions. The social worker and house staff were left with the residual effects of the conflict between the two primary actors, the wife and the attending physician.

Medical personnel identify patients as "toxic" because they actively obstruct professional efforts, or have rejected traditional medical treatment in the past. Patients or their families are blamed in such cases rather than the seriousness of the disease. However, patients have equivocal enthusiasm for mainstream medical technologies. When their initial course of treatment was alternative health care and they present themselves with an advanced disease, doctors are particularly frustrated

because they must deal with a situation they feel could have been avoided. In such circumstances, the physician's chances for achieving success have been limited by the patient's resistance to traditional care.

Patients Who Seek Non-Traditional Care

Several patients who had rejected traditional medical treatments at the time their cancer was diagnosed were referred to SCS. One striking example was a middle-aged woman with metastatic breast cancer who was referred for pain control. When originally diagnosed, Mrs. T. had decided against the recommended surgery in favor of a non-traditional dietary treatment. This patient remained overtly skeptical about traditional medicine and continued her non-traditional therapies while she was in-hospital. She had various health food preparations at bedside, which her family obtained for her. I made the following comments in my log:

> Observed with a staff nurse, Mrs. T. questioned L's authority to administer medications through her IV lines. She repeatedly asked the nurse about the dose, claiming that the doctor had not ordered the dose the nurse was about to administer. L. explained how orders were written in the medication book by the house staff, that they were the ones responsible and that she was sure it's what her doctor wanted her to have. Mrs. T. said it was the wrong dose and not what her doctor wanted. Eventually L. left the room without giving the medications. The nurse waited for me outside the patient's room. She said she was really angry at that woman and her whole family. Her wound was disgusting, she never accepted anything without a fight. It was her fault anyway not to do what she obviously should have done in the first place. They weren't stupid

> people, after all. She said that Mrs. T. was a great case for my study, since she was terrible and brought the whole thing on herself. I asked G. (SCS nurse coordinator) about the wound and why they couldn't operate now. She said when you don't operate on these cancers and they are just allowed to grow, that the cancer can actually grow through the outside of the body, leaving a fulminating wound which is very difficult to care for. She said that one of the things people don't think about when they don't treat is what untreated cancer can become. She said she used to see this kind of thing at CH with elderly, single women who denied their breast cancer until it had reached that point.

Mrs. T. was an exceptionally difficult patient, not only because of her obvious and outspoken skepticism of traditional medicine, but because the staff saw her and her family as responsible for her present condition and ultimate death. From their point of view her actions had prevented -- and continued to prevent -- health workers from applying their technologies.

In addition to circumstances where patients or families are blamed for "toxic" behavior, similar situations can develop when symptoms cannot be controlled by routine palliative interventions. In these cases the patients are not blamed unless they obstruct staff efforts to apply treatment. As we have seen, problems with "toxic" patients are not limited, but can have consequences which reverberate through the life of the floor. As evidenced in the above discussion, when interventions are no longer effective, patients become problematic for hospital personnel. To some extent this point on the illness trajectory is routine and expected as diseases progresses, but from the perspective of hospital workers

facing a barrier to the pursuit of their curative goals, the situation presents them with an hopeless situation. How all professional groups manage this hopelessness inherent in their situation will be discussed in Chapter Seven.

Sources of Disrupted Routines

Patients and family members are one source of work disruption for care givers, but other sources compound staff problems as well. Disease characteristics can make unusual demands on staff. Also, institutional forces can create problems for staff. These problems can develop from collegial and peer interactions or they can involve institutions outside of the hospital. When the source of the disruption is attributed to institutional forces or the disease itself, patients are forgiven. When the patient or his family is identified as causing the problem, they are not forgiven.

Obstructing Worker Activities

In the following example, which both a nurse and a social worker independently suggested for this study, a patient's wife disrupted the floor routines for a series of professional workers. The patient himself was an agreeable and cooperative man with adenocarcinoma of the lung. His wife, on the other hand, was not

only very anxious and protective about her husband's illness, but actively obstructed the work on the floor. The most striking feature of this behavior was her posting signs on her husband's door which told the staff to keep out. As described by the floor social worker:

> She comes across like a ton of bricks. That's the way everyone has experienced her. The signs are one more brick for people...She's tended to isolate herself and her husband and the signs being the number one way of keeping people out. The signs are a sleeping face with eyes drawn and "zzzzzz," or the other one was: "Roses are red/Violets are blue/Keep Out!/This means you!"

The wife mistrusted house officers and nursing staff and monitored their access to her husband's room. She preferred to provide nursing care herself and wanted only her private oncologist to attend her husband. The wife lived in the patient's room for the 35 day hospitalization; she had food delivered from home.

Besides the affront to civility and disrespect which the signs communicated to the floor staff, the wife's gatekeeping activities had specific consequences for the work routines of house officers and nurses:

> I just read the signs and I laughed to myself. In a way it makes you a little uncomfortable because you're thinking to yourself that she doesn't want you there. She doesn't want you to spend too much time there. He's not eating and losing weight. So I'd try to encourage him and make suggestions to her about fruits and things like that. And she listens at times but you know she doesn't want you there...She was really

> anxious when I went in to check his orientation. You know, I'd ask him his name and did he know where he was or whatever, because when he first came in he said he was in his apartment. And when I asked him his name, he told me somebody else's name. So when I tried to ask him the next day, she said, "No, don't ask him that. I can't take it when you ask him that."

In order to function with her patient, this staff nurse revised her usual routine to accommodate the wife's behavior:

> She's at the door and when she sees you coming, she stands right there by the door and she yells at you not to come in. I just knock on the door and I go in. I say, "I have the med," or "I have such-and-such to do." I give her a reason why I have to go in...I haven't lost it with her because, as I say, she's concerned. But sometimes I just say to myself, "This lady is off-the-wall!"

When she defined the problem as an illness, the nurse could forgive the wife. Attributing the behavior to psychopathology allowed her to continue to function in this hostile context without losing her professional demeanor.

Certain professional activities are prescribed in floor life. "Rounding" on patients is an essential ritual through which house officers assess clinical status. Also, house officers must routinely see patients in order to communicate their observations to other personnel, including the attending on a private service. Since they are responsible for the stability of patients in their care, denied access seriously jeopardizes their professional status. A house officer, piqued by the situation described above said: "How do they expect you to round on that man, we can't even

get in the door."

These problems for medical and nursing staff created opportunities for the social worker. She was also affected by the wife's obstructive behavior but by converting the wife's problem into a therapeutic opportunity, she applied an innovative strategy which produced a successful outcome:

> I initiated it. I asked Dr. B., "Shall I see Mrs. M.?" because the staff didn't actually bring it up as a problem. He said, "Well, I'll talk to her, yes." But she told him that I was supposed to come ten days ago. So I already thought she was angry with me, what was I going to do. So, I said to Dr. B., "Is she a little bristly?" I saw the sign on the door. I usually knock, even if it's a four-bedded room. She was right there when I pushed open the door. She said, "I can't talk to you, I'm busy right now." She cut me off, like that! So I said, "Here I am, here's my name, I'll be on the floor an hour or two. Please find me." And she did. I brought her down here, I gave her the option of where. She had a very closed manner. She had dark glasses on. She spent the whole time verbalizing her anger, her fear -- the nurses, the interns. She loves Dr. B."

The success of the social workers' interventions was apparent in changes in the wife's behavior. She ultimately took down the signs and was able to appreciate the needs of staff to proceed with their work routines.

Mrs. M's profound anxiety about her husband's illness led her to behave in ways that kept the staff from proceeding with their work in an efficient way. Although some staff attributed her behavior to psychopathology, others blamed her for willfully disrupting normal routines on the floor. The wife kept many staff

members from accomplishing their work. Not only did she keep staff from entering her husband's room, she also kept pieces of equipment in the room which should have been generally available to other patients. For example, she left a transfer cart next to her husband's bed at all times, a trivial, but annoying example of how she wrenched control from those caring for her husband and, in the process, disrupted the life of the floor.

Routines for Disclosing a Patient's Prognosis

Routines for disclosing a patient's prognosis are an important issue in terminal care. As described in earlier chapters, whether or not doctors should inform terminally ill, or for that matter any cancer patients, about their illness and prognosis was an ardent topic of the death awareness movement beginning in the mid-1960's. This literature described the reluctance of health personnel to disclose information to patients. The reasons for not informing patients were described in the structural dimensions of the doctor-patient relationship or in routines for making patient management easier. Controlling uncertainty gave the physician increased power over the patient and, consequently, over disease management (Quint 1972). Keeping patients at the stage of denial simplified the work of nurses and doctors when patients were hospitalized since it limited expressions of grief or anger

(Mauksch 1975).

This study confirms a shift to more direct discussions with terminally ill patients about diagnosis and prognosis reported in recent studies (Carey and Posavac 1979, Novack et al. 1979, and Veatch and Tai 1980). As expressed by a head nurse on a private medical service, "the era of the big secret is over." A significant force in that transition from "closed awareness" to an "open awareness" (Glaser and Strauss 1968) norm is the present impact on floor routines for patients' knowing or not knowing their disease status. Earlier studies have explained this phenomenon because the health consumer, thanatology, and hospice movements have created a productive environment for doctors sharing information with their patients (Novack et al. 1979, Veatch and Tai 1980).

But these movements have coincided with the development of cancer treatment technologies which almost require open awareness for patient cooperation. Because consumers know about cancer treatments and their often impressive side effects, it would be difficult to treat patients who were naive about their illness. Also, open awareness is not universal and depends on individual physicians' perspectives and, to some extent, their assessment of the patient and family. Yet these forces may be encouraging different normative patterns than existed in the past. According to a senior staff nurse, "We rarely have a case where the patient

is not told at some point. The oncologists may go gingerly at first, but we do everything we can to get them to level with the patient because there are too many slipups. It's ridiculous, once in two years that happens."

Thus, the extraordinary case is the one where a patient is not informed, which has become the problematic, non-routine situation. The difficulties created were apparent in the case of a middle-aged woman with lung cancer whose family did not want her informed about her illness. The situation proved exceptionally complicated for all professional groups, since it required personnel to monitor their usual behavior. When the attending physician accepted the family's wishes not to inform the patient, nurses, social workers, and house officers were forced against their desires to participate in the obfuscation. The "toxic" situation this created ended when the patient died, a death that came sooner than expected, much to the relief of floor staff. As expressed by a staff nurse:

> I think it's really difficult to carry on the routine of the floor when you can't mention the word "cancer" to the patient. That's one illness that is ordinarily talked about at bedside. All the staff had to be alerted that she didn't know the diagnosis. And it just made it a little more difficult that you had to remember an extra thing again and again. It just disrupted the whole routine of the floor. The daughter made so many demands on the staff -- not to do this, not to do that."

The house officers objected to the position taken by the attending:

> The doctor had written in the chart, "The patient is not aware of diagnosis." The residents were outraged. They were just offended that here was this woman who was able to understand her diagnosis and make decisions whether to be treated or not and he did so much dancing around the issue -- constantly. They felt it wasn't justice to the patient -- It was really horrible to the patient."

The family's desire to keep the patient uninformed was also "toxic" for the social worker in this case. In her assessment, the patient had been an active person who was oriented and alert. The worker thought the patient's sudden dependent behavior was a by-product of the family's overprotectiveness. It seemed "a little crazy" to her that the family did not want her to be informed, since she appeared to be a woman who could "handle her illness." While extremely dependent behavior on the part of the patient compounds staff's work, the central difficulties here were maintaining the conspiracy and the daughter's efforts to orchestrate it:

> The daughter had called before she was admitted. She said she was very concerned about her mother. The doctor said he suspected cancer. She said she heard social workers could go and see patients and would it be all right if I could go and see her mother. She was truly overprotective of her mother. She kept emphasizing, "If you go in, what will you say to my mother?" I think she didn't want me to confront her mother with the facts. On a first interview, I am never very direct about the diagnosis. The daughter approached other staff members, "Don't talk about this, don't talk about that." Later on, the daughter would whisper to me, "I'll call you in the morning, I'll call you later on."

The family was spared confronting the problem of treatment in this instance, the patient was found unacceptable for chemotherapy. A house officer reported: "After the 'tumor' was discovered, we thought about chemotherapy. But the patient wasn't strong enough to do chemo at that particular time. The daughter was relieved that we wouldn't have to tell her mother because she knew she'd become aware of what was happening." While it might be argued that some families have been caught in a time warp between old and new norms in terminal care, the results of their desires have consequences on the floor. Had Mrs. S. survived longer, the family might have become socialized to the new normative expectations of the staff.

Problems emerge when different attendings involved with the same patient have different opinions about disclosing information about an illness. Even in a hospital culture which encourages disclosure not all doctors will discuss a negative prognosis with a patient. Also, individual doctors have different styles in discussing prognosis. I have overheard physicians equivocate or avoid both the patient's and the family member's questions. Even with the same patients, various consultants attending the patient may take different positions about what and how to inform patients.

The examples in the previous section demonstrate how the toxicity of patients or their families affect the work routines of floor staff. Problems in routine disruption are particularly

apparent among the terminally ill. The palliative care needs of these patients generally require response times which are much more spontaneous than the usual acute care patient. For example, acute episodes of pain require rescue doses of narcotics which do not conform to the scheduling routines for the administration of other drugs. Also, the affective needs of patients for psychological assurance and the impact on family members of the emotional tenor of the death process in hospital can precipitate aberrant behaviors.

The Impact of the Environment on Terminal Care Routines

Limited resources within the hospital can also limit the capacity of staff to respond appropriately in terminal cases. The constraints of community services can also generate problems in work routines on acute care floors.

A universal complaint among the floor staff interviewed for this project concerned lack of resources and structural barriers that prevented acquiring necessary materials. Pillows, blankets, special diabetic diets, dental consultations, supplemental nurses assigned to high acuity floors, educational programs and specialists for terminal care, x-rays, stat test results, and ordinary laboratory results were among the necessities which at one time or another staff said were difficult to obtain. "Just the

ordinary things, everyday things...and when all of it seems to combine in a mess, it's horrendous." When simple equipment is unavailable, staff must revise routines to accommodate limited resources.

Social workers, in particular, must cope with the limited community resources to do their work. All of the social workers interviewed for this study identified this deficiency as a problem in their work, particularly with patients who required long term or terminal care. Long waiting periods for placement complicated their work. House officers pressured social workers to free beds, which became the focal point of the conflict. Social workers also found their work complicated or undone by physicians-in-training who, from the social worker's perspective, did not appreciate the subtleties and complexities of public and private systems. After-care plans hang on a thread of time and cooperation among a number of providing agencies. Among many examples of this issue, the following illustrates the frustration of social workers in health settings whose work can be undone by the naivete of other staff and their ignorance of inter-institutional problems:

> I have a cancer patient, lived alone, did not have any family here -- has a daughter here, but not involved with the family for a long, long time. The church the patient belonged to was very concerned. She worked at CH and for weeks on end we were working. We had worked on an elaborate plan for her to get help <u>this</u> week. Not last week because it couldn't be arranged because of the holiday. It was all documented in the chart, why the woman couldn't go home, etc. Yet Monday, I came to work to find they'd discharged her on Saturday. Without Visiting Nurse, without Cancer Care, there was no one to give

> her insulin on Monday. So then I had to go through big contact with every organization, trying to get her services. And all the people I spoke to earlier, yelling at me for not providing what I said I would provide. And I had no control over it.

Social workers are caught between the institutional expectation that medically stable patients should be discharged and the fact that the patient's medical condition may require scarce and elusive after-care services. Doctors may not appreciate the admission criteria for other institutions. For example, one physician felt his patient should go to a special hospital for advanced cancer patients. The hospital required a tissue diagnosis as an assurance that he was indeed terminally ill. The doctor refused to perform the invasive procedures necessary for documentation because he did not feel it was in his patient's interest. The medical director at the terminal facility rejected the patient for lack of a tissue biopsy, and the social worker was caught between the opposing medical perspectives. "Toxic" cases for social workers frequently involve formidable institutional barriers to negotiate.

For all hospital professionals, "toxic" dying patients and their families are the most complex and difficult to manage. The attribution of "toxic" depends on interpersonal interaction between the patient and family and the individual staff member, mitigation of the work for the staff member, or the course of the disease. The same series of variables determines the attribution of an "ideal" label to terminally ill patients.

Ideal Terminally Ill Patients

Personal Gratification and the Terminally Ill Patient

> And what if the patient, whose sores you're washing, does not at once show how grateful he is to you, but, on the contrary, begins to torment you with his whims without noticing or valuing your charitable services? What if he should start shouting at you, demanding something from you rudely or even complaining to your superiors (as often happens when people are in great pain) -- what then? Will you still go on loving him? And, you know, I came with horror to the conclusion that if there were anything that could instantly damp my ardor of the "active" love of humanity it would be ingratitude. In short, I can work only if I am paid. I demand payment at once, I mean I want to be praised and paid for with love. Otherwise, I am incapable of loving anyone.
>
> Dostoyesky, The Brothers Karamazov

Few professional rewards exist for health workers caring for dying patients. Terminally ill patients present hospital personnel with an image of failure that does not support the idealized outcome of professional activity. Also, since hospitals are designed for acute interventions, routines are often disrupted by the presence of those who do not conform to this care model. Long delays in discharge planning or flexible time needed for palliative interventions are not compatible with the time constraints in acute care hospitals. However, personal rewards when families and patients express appreciation are profound mitigating factors against these problems for terminal care providers in hospital. Conversely, the absence of gratitude exacerbates the intrinsic

difficulties of death work. Also noted in this study were the salutary effects of heroic behavior and socioeconomic similarities to the care provider. These affective characteristics were powerful indicators for ideal categorization of terminally ill patients.

Gratitude is the immediate payment health workers demand from patients, the explicit currency for providing care, and the essential compensation which supports the altruistic motivation which attracts workers to the helping professions. Posted notes of thanks from patients and large boxes of candies sitting open at nursing stations are concrete manifestations of gratitude for valiant work of the staff. These emblematic expressions reinforce the fact that the work has been valued. On the other hand, when patients or family members devalue professional work or question the competence of professionals, they evoke profoundly negative responses. The following example illustrates the intense feelings of rage at an ungrateful family expressed by a senior resident after his own futile efforts to revive a dying patient:

> I had this patient on the renal floor, a guy with end-stage renal disease and lung cancer and biventricular heart failure. He was really sick as a dog. And we were doing all sorts of things to turn this guy around. And he was a nice guy but his family was so incredibly obnoxious. There was always an adversary relationship between house staff and the family. It was always what we were doing <u>to</u> him -- not that he had all these terrible diseases and what we were doing to <u>help</u> him. It was as if we had inflicted these terrible problems on him. This guy arrested on dialysis with the family there, and we were working to bring this guy back, and he finally died. And coming out of the room the family accused us of having killed

> him. It was incredible. I felt incredibly angry at that family. I basically didn't deal with them at all because they were so out of line. I thought at that moment I wouldn't stoop to their level. I just let them blow off their steam. The house staff were the hired help.

Professional health workers interviewed considered gratitude as an indicator of the ideal patient. Expressions of gratitude could override other "toxic" dimensions. "Toxic" labels were dissolved when a patient or family member directly expressed gratitude for care. For example, when the patient whose family protected her from knowing her poor prognosis was moved to another floor, a nurse on that service claimed she thought the family was "wonderful," because of their frequent expressions of appreciation.

> They were extremely nice people, so it was hard, they were very demanding and very hard to deal with, in one respect. But they were very appreciative in another. They were wonderful, really. And I kept thinking how nice they were -- a lot like my family. It may have been very frustrating and time consuming but I just felt for them.

Patient Identification: The Heroic Patient

Not only was the family presented above appreciative but the nurse was able to identify with them. They reminded her of her own family. While many have observed that health personnel are more positive about patients who have similar demographic characteristics, the ability of this identification to override other negative qualities, such as demanding behavior, is striking. An attending physician frequently observed in this study had a

special affinity for patients with his own religious and social background. He would visit these patients often and listen to their complaints about pain or the inefficiency of nursing staff, while he would spend very little time listening to the complaints of other patients. The gesture of pulling over a chair to the patient's bedside was an indicator of the willingness of the physician to share social parity and human concern with patients.

Besides expression of gratitude and identification, dying patients who heroically confront their deaths and endure their pain with stoicism were also labeled "ideal." A 60 year old man with metastatic prostate cancer and intractable bone pain was a favorite patient of both the SCS team members and hospital staff. This man had been the first Black man to play professionally in a particular competitive sport, and he and his family brought to his illness qualities of persistence and endurance which were defined as "heroic" by staff. His past experience in professional sports was a reference point for his care givers for his heroism in the face of advancing disease. These aspects of his personality were frequently described in SCS rounds. Both SCS care givers and the nurses and doctors who cared for him during his frequent hospitalizations spent unusually long periods of time with him in spite of the fact that his symptoms became worse over time and his pain proved increasingly unresponsive to palliative interventions. One SCS physician arranged a compassionate plea to the Food and

Drug Administration for permission to dispense a special non-steroidal drug to this patient. This process involved extra paper work and special efforts to get the drug to the patient, which were continued even when he returned home to a neighboring state. This was the only case I observed of such efforts made on behalf of an SCS patient. In this instance, the "heroism" attributed to this patient overwhelmed the usual attribution of "toxic" status for staff, in spite of persistent interventive failures.

The Remarkable Remission

The final ideal patient type observed in this study constituted those with advanced malignant disease who survived what was thought to be a terminal cancer. A unique group, these patients had unexpected and remarkable remissions which confounded the prognostic wisdom of experienced practitioners. Even more than grateful or heroic patients, exceptional survivors functioned as talismans for care providers, generating speculation about the causes of their remissions and frequent reviews of the course of treatment and personality characteristics of the patient. Consistent with recent attempts to correlate psychosocial variables with successful medical outcomes (Cassileth et al. 1985), SCS team members reviewed the personality characteristics of these

patients. Nonetheless, the attribution of success for exceptional patients was located within the medical intervention. One SCS physician described an elderly patient with tumor from an unknown primary source:

> There was so much tumor it was difficult to tell whether it was breast or ovarian. It either came from her original breast cancer or from an ovarian primary. There was so much tumor that it was difficult to be certain which of the two this represented. The amount of tumor she had, and the rapidity with which it was growing, and the fact that she was so terribly sick and obstructed, made everyone feel that she had only days or weeks to live. She had this surgery and then she was started on Tomaxifin -- that seemed like a relatively benign thing to do, on the assumption that it was breast cancer. She seemed to do much better. She had a colostomy to relieve the obstruction. She doesn't recall our concern that she might die. She states she remembers little or nothing of the hospitalization. Mrs. P. regards herself as an unusually anxious person. And she really is. She becomes almost paralyzed with anxiety, so it is particularly interesting that someone like that should come through this kind of illness so well.

While this senior attending physician could recall patients historically who had remarkable remissions before chemotherapeutic agents were used for cancer therapy, he attributed the patient's response to the medical intervention:

> I really think that she has a tumor that was responsive to one of the agents she received. You know this whole issue of cause and effect. The fact that we have to make such judgments statistically. We used Tomaxifin because x% of breast cancer patients respond to it. Therefore, when someone responds to it and we don't know of any variable where the tumor has been growing and we introduce this agent and the person gets better. That's the best we can do in terms of reasoning in a clinical situation. So I'm inclined to think that she was just

getting worse daily and these agents were introduced and all traces of the tumor disappeared.

In another instance, a 50-year-old woman with advanced breast cancer was referred to the group for psychosocial support for depression. The patient was described to the SCS nurse coordinator as "pretty near the end" by the head nurse. After the nurse coordinator and I visited the patient and gave our usual description of the service, the patient's depression lifted and she went on to survive for more than two years. She even resumed part time work as a nutritionist during this period. Much to our surprise, the head nurse attributed the fact that the depression lifted and later the ultimate success of this patient to that limited intervention.

Linking a medical intervention or psychological support to a successful outcome, which in these examples were not logical certainties, buoys the practitioner who must often deal with failed efforts in "hopeless" cases. It is therefore not surprising that these patients, along with others who outdistanced predictions of their longevity, were frequently discussed in SCS rounds or informally among staff. In some instances, these patients were remembered long after they were on a service. The relative impact which positive patient outcomes have in the face of such limited success reflects the problematic nature of this work for people committed to health care.

Conclusion

This chapter has reported on observations and interviews with doctors, nurses, and social workers at EEH about their work with terminally ill patients. Using an original typology which considered patient and illness characteristics within the context of staff needs for interventive success, stable work routines, and affective rewards, the discussion centered on the determinants of professional definitions of "toxic," "routine," and "ideal" patient types.

CHAPTER SIX

WORKING WITH AIDS PATIENTS: THE "TOXIC" DIMENSIONS FOR HEALTH WORKERS

Introduction

AIDS patients as a group are likely to be considered "toxic" patients for several reasons. Because there is no known cure for the disease, professionals caring for AIDS face a situation where, no matter what they do, the patient will ultimately die. Because AIDS is a new disease, and considerable uncertainty existed, and continues to exist about its processes, it has required revised routines for management of patients in hospital. With this syndrome, patient care is affected by the emotional responses which the disease evokes. Working with numbers of young, previously healthy patients who now face death intensifies responses to work with these dying patients. The fact that most AIDS patients come from socially stigmatized population groups further complicates the responses of health workers. Despite the fact that disease is so "toxic" to those working in acute care hospitals, some individual patients are viewed positively by staff members and, at least during the period of this study, health workers were observed making extraordinary efforts on their behalf. The conditions under which patient "detoxification" takes place are described in this chapter.

As in Chapter Four, the characteristics of "toxic," routine, and ideal patients are those identified by doctors, nurses, and social workers interviewed and observed as they worked with the terminally ill. Using this typology as a framework, I will present data on the issues that confront professionals in their work with hospitalized AIDS patients.

Ideal, Routine, and "Toxic" AIDS Patients

Technological Impact of an Inevitably Fatal Disease

In general, according to informants for this study, successful application of their respective technologies was the single most rewarding aspect of professional hospital work. As indicated in previous chapters, every medical and nursing informant interviewed said they gained the most work satisfaction from curing patients and sending them home. Social workers also identified with the rewards of sending patients home well, but soon their efforts are adjunctive in this process. All professional health workers want patients to benefit from their efforts, so an important characteristic of good patients is that they respond to the work of staff to cure them and return them to the community. In order to achieve their goals with patients, doctors, nurses, and social workers need effective technologies and a fertile context in which

to apply them. Good patients are physically responsive to treatment. Short of that, they do not obstruct or frustrate the efforts of staff to apply their technological expertise. Institutional and community supports must enable technological application as well. For all staff, frustrations in accomplishment, either because of limited knowledge, inadequate institutional or community supports, or patients who obstruct professional efforts were seen as barriers to success.

The Impact of AIDS on Physicians

The goal of curing patients represented a universally held ideal throughout private and pavilion medical services at EEH, although patients cared for were rarely "cured." As Strauss et al. (1985) point out in their analysis of the organization of medical work, even in the face of increasing prevalence of chronic disease, medical personnel still retain the imagery of treating acute illness. What doctors in hospital treat are frequently, in fact, acute episodes of chronic diseases. Because of this reality, medical staff must partialize technical success on an episode-by-episode basis or otherwise redefine "successful outcome" according to incremental standards. While these partialized "successes" are the successes most often actually accomplished, the ideal of a more global success remains an elusive goal, especially

for AIDS patients.

AIDS offers a powerful example of the relationship of patient status to existing professional interventions. The most striking characteristic of AIDS at present is its inevitable fatality. But technical failure extends beyond the fact that medical personnel do not have effective interventions against the disease, so that no patient has been cured. AIDS has also frustrated professional staff because of inadequate resources to manage this illness through the serial hospitalizations which characterize the trajectory. The youth of the patients and their "deviant" life-styles, as well as concerns about the mode of transmission of the disease, have also compounded application of available technologies.

As discussed in the preceding chapter on good and poor terminal cancer patients, one indicator of ideal status for a dying patient is a remarkable remission. Unfortunately, medical treatments that have been used against the serious events which characterize AIDS offer no hope that patients will be cured. Because there is presently no known cure for AIDS, the best expectation for physicians is for treatment to prolong life or for palliation of symptoms. The possibility that a patient might have an unanticipated positive response does not exist in this treatment context. Consequently, the functions of such hopeful fantasy to keep medical personnel engaged with even "hopeless cases" does not

exist with AIDS patients. All AIDS patients are seen as ultimately "hopeless." An attending physician whose research activities required him to follow a large number of AIDS patients said:

> You realize, what makes this hard is I hate taking care of these patients. Whatever you do, they all eventually die. I don't enjoy it. It's not fun. It's almost a social obligation. It's almost like doing it for the service. You do it and continue doing it. There is some reward in the altruistic. It's almost like being a voluntary fireman. I don't know if people enjoy being voluntary firemen.

Clearly, one of the reasons taking care of AIDS patients is objectionable is because of the futility of medical technology to change the ultimate course of their disease. Observations of interactions between physicians caring for AIDS patients reflects the same hopelessness. Comments such as, "Does it really matter?" or, "We're talking about AIDS here!" or grimaces which express the futility of intervention pepper case discussions about AIDS patients.

The Impact of AIDS on Nurses

Nursing staff also experience the devastation of inevitable patient death as they watch patients decline through serial hospitalizations, much the same way as cancer patients are admitted and readmitted to hospitals over and over again. But technological failures with AIDS patients take on additional and professionally

specific dimensions for nursing staff.

The natural course of the disease and the limited institutional resources for AIDS patients present profound management problems for nurses. Particularly at the terminal stages of the illness, symptoms such as mental status impairment, decubitus ulcers, and chronic diarrhea make it impossible for nurses to meet patients' needs with resources at hand, particularly on services with concentrations of AIDS patients. Floor routines were disrupted because inadequate nursing staff could not manage the complex and demanding manifestations of the disease.

Because of a large number of private rooms on one patient floor, the floor consistently housed a high proportion of patients with AIDS who required isolation. The head nurse explained:

> We have had as many as 12 boarders on a 21 bed unit and out of those 12 boarders, 10 have AIDS. That's half your floor. With two nurses that's a lot of care. And I'm talking about sick patients who can't care for themselves. Where one dies, you know there are going to be two more to follow him. You see them going downhill, you see them deteriorate. You really don't want to go in the room day in and day out, because you're just going to see them die. Patients like that are in diarrhea from the minute the shift starts to the minute it ends. You're in there every twenty minutes, constantly.

This example graphically portrays the same sentiments the physician conveyed in his comments about the futility of caring for AIDS patients. No matter what the physician does, the patient dies. No matter how many times a nurse attempts to clean the patient, his uncontrolled diarrhea soils him. The futility of

performing the cleaning is exacerbated by the fact that other patients wait with the same prognosis and symptomatology and that the usual staffing provided to the floor is woefully inadequate for reasonable coverage. This simple example provides a powerful illustration of a concept of toxicity of the illness for workers, along all three dimensions. The presence of large numbers of AIDS patients disrupts nursing routines and care plans for less ill patients. Even the affective rewards of gratitude and patient identification are absent with these patients, who at the end-stages of the disease are non-responsive, encephalopathic, and possibly contagious as well.

The Impact of AIDS on Social Workers

As for social workers whose professional technologies can be more successfully applied to AIDS patients, theirs is a difficult task as well. For example, when they cannot locate community service or hospice programs which accept AIDS patients, their efforts at after-care planning are very stressful. They have to scour the city for possible programs and at the same time contend with in-house pressures to clear hospital beds. As with nursing staff needs in the previous example, social workers rely on institutional and community supports for effective functioning. Clearly, no matter what efforts social workers make to assess

patients' needs and their personal resources, if community programs are not available, their efforts are bound to failure, or at least long delays. Just as the physician lacks the medical resources to effectively treat AIDS patients, the social worker lacks the community resources for effective planning.

In this study, social workers claimed that physicians undervalued the reality of limited resources. Both house officers and attending physicians "handed over" problematic situations to social workers. While social workers might complain about this phenomenon, in many cases these tasks, including discharge planning or patient care, correctly belonged with social work and nursing staff. Serious problems arose, however, when doctors told patients resources existed when in fact they did not. In these instances, social workers were left to search for special housing or community supports which were not available. Consequently, they bore the brunt of patient confusion and anger when the worker could not produce the necessary resource.

For many social workers, discharge planning delays for other terminally ill or chronic patients are usual, so that this problem is not unique to AIDS patients. According to one social worker: "It's different for me than for the doctors. I know that if I just stick in there, eventually something will come up. Or sometimes, the patient just dies." Queuing for limited community resources means that the social worker can, in some case, wait out the need

for an acceptable after-care plan. Also, unlike physicians, when limited community resources frustrate their efforts, social workers can offer patients supportive intervention, which to social workers at least is an acceptable and, indeed, valued professional task. An experienced social worker described this process:

> I remember sitting with this guy. He was thirty-eight years old. He had to stay here because he was homeless. So we couldn't send him anywhere. I remember going into his room each day. The guy had PCP. I was sitting with him for a half an hour daily for a whole month and helping him verbalize so he could come to term with his illness.

In this case, as in others which will be described later, the social worker acknowledged a physical aversion to the patient, and she was concerned about frequent contact with an AIDS patient. Her work was also hampered by the limitations of resources. Yet, she was still able to serve a valuable professional role which gave her personal satisfaction and enabled her to sustain her daily visits.

Another social worker reported a similar "success" with an AIDS patient, where her empathic and psychosocial assessment skills provided a satisfying outcome:

> Some people come in and they don't know the diagnosis. We've had people come in and they've had no idea they had AIDS. I remember this man. He was self employed. He worked in the theater. He was a set designer and he was very pleasant the first time we met. Then a couple of days later, he was given the diagnosis and became very, very angry — very hostile. He just didn't want to talk to me. He said he was just fine. His finances were in order. Everything was fine and he didn't need a thing. On the first contact he had told me about his mother. So, I got in touch with the mother and he rejected me,

> like that! She was a very nice woman. She said to me, "He's really not like that. He's really a nice person." Anyway, he got over his anger in about two weeks. Then he went home to his mother and he called me. He said he was sorry he put me off. Ultimately we got disability and transportation. He was so delighted and happy. The mother made a point to come in and see me. That was a really rewarding case.

Multiple Failure for All Professional Groups

The following example demonstrates multiple technological failure with an AIDS patient. What makes the case so striking is that in spite of compounded failed efforts to help the patient, both socially and medically, the staff persisted in trying to resolve his problems. Even more confounding is the fact that the patient was universally identified as "demanding" and "difficult." The discontinuity between the staff's perception of this patient as "toxic" and their prodigious efforts on his behalf suggest the special conditions under which staff will transcend the "toxic" label and demonstrate a very high level of commitment to patient service.

> Mr. C. was a middle-aged AIDS patient suggested for this study because of his unusually demanding behavior. The patient was well known on several medical floors where he had been admitted for treatment for episodes of PCP. Stories of his persistent calls to all manner of hospital personnel were legion. All three staff members interviewed about the patient remarked that Mr. C. spent most of his day telephoning attending physicians, hospital administrators, patient services representatives, and social service workers. With each call he would complain about problems which might be described as routine and review the responses of previous personnel. According to an attending physician caring for him, "It's better to come early in the morning because if you come late in the afternoon you have to

> hear what each person has told him. So, by 5:00 p.m. you can also spend an hour and a half." The patient had been married and had a child who lived in Florida. This son was to undergo cleft-palate surgery which was scheduled to take place while Mr. C. was in hospital receiving a course of amphotericin B for cryptococcal menningitis. Mr. C. wanted to travel to Florida to be with his son for the surgery. A medically acceptable discharge would have involved locating a vendor in Florida which would continue the anti-viral treatment for Mr. C. as an outpatient. Although an attending physician told Mr. C. that the social worker would have no trouble locating such a vendor, the task ultimately proved impossible.

Despite failure to locate a company to take on this technical aspect of Mr. C.'s care, staff efforts persisted as described by the social worker:

> Our home care nurse was working extremely hard to work things out and it was not within her job description to do so. And she was taking the time with companies to work things out. One of the companies came and said they would not take cash or any form of money. Mr. C. threw that person out and ended up bad-mouthing the company -- bad-mouthing the home care nurse.

The same social worker analyzed the continuing efforts staff members made on Mr. C.'s behalf:

> In the whole scheme of things, everything that was hoped for was ultimately not going to work out. Everybody, including the patient, knew it wouldn't do any good. It was going to be fatal anyway. On the whole, everyone was fighting a losing battle and that was difficult for the staff to deal with. Here we were, all pushing him to have this great amphotericin -- I think Dr. L., the attending said also, if he doesn't have it his life will be X amount of months as opposed to three months.

Mr. C. did sign out against medical advice, which was treated as a

minor technical infraction rather than a major failure to follow medical advice. In fact, some members actively encouraged him to visit his child:

> In any other situation, with another kind of patient, it would be different. If he didn't have AIDS, but another disease, we probably wouldn't have encouraged him to leave the hospital. Barring anything else, we might have even had him declared mentally incompetent. I didn't spend a lot of time keeping him in the hospital. I'd rather spend the time getting him out. He is going to die. His child is important to him. Two weeks with his child is better than 12 weeks in the hospital. We're not talking about saving this guy. First of all, the therapy has a 50% chance of working. I should tell you, at this time, he is still positive for crypto [cryptococcal meningitis] — so the therapy was completely ineffective. Except that it prevents him from dying. As long as he's on something he'll live until he gets something else that will kill him. So it's very temporizing — it's not curative. Plus, leaving the hospital will not mean that he will die. In fact, he did not die. He was no worse off than if he'd stayed in the hospital.

Two sets of professional interventions failed in this example. A potent anti-viral drug, while not administered as curative therapy for AIDS, failed to have the anticipated effect against cryptococcal meningitis. Resource location failed both social work and home care staff. Early in the process of community resource development, particularly in a community less affected by AIDS, resources for specific outpatient needs were unavailable. Yet the physician, social worker, and nurse all persisted in pursuing their efforts beyond the point where it was clear they were not efficacious. These efforts were jettisoned when a higher value was identified — that is, seeing to it that Mr. C. had an opportunity

to be with his ailing son. At that point, staff members took the very unorthodox, but possibly relieved, position of encouraging a patient to sign himself out of the hospital against medical advice.

In many hospital settings, house staff gets rid of, or "GROPs" (Mizrahi 1986) difficult or unresponsive medical patients as a routine management technique. At EEH there was little evidence that this exceptionally demanding patient was encouraged to leave because staff wanted to be rid of him. After a long and unsuccessful process of resource identification, the staff's encouragement of the patient's leaving the hospital reflected their evaluation that the drug therapy, home care, and social services were ineffective and their continued pursuit was a barrier to the patient's desire to be with his child. "Groping" implies that the interests of service functioning override the best interests of the devalued patient. In this case, both the staff and the patient chose an unconventional but mutually agreed upon resolution which all parties, including the patient, felt best served the situation.

Rather than GROP the patient because he presented problems, the staff identified an affective reward, which was all that could be salvaged. Thus, the fact that Mr. C.'s leaving the hospital provided staff with a respite from their frustration was probably only incidental. According to the social worker, "My heart went out to him. His time -- that's important. What's interesting was we all felt this could not be arranged. However, we all tried very

hard." Using a strategy that redefines the goals of treatment to maximize the quality of life, the various hospital staff caring for Mr. C. were able to exchange the usual areas of achievement, that is cure or effective discharge planning, for a more personal reward.

Throughout the study, I noted similar efforts by house officers, social workers, and nurses involved with AIDS patients to ferret out what limited goals might be achieved with these patients. On clinical pharmacology teaching rounds, interns and residents queried the faculty on available spaces in research protocols for their AIDS patients or even sources for experimental drugs outside of the United States. One can speculate that the culture in this acute care teaching institution encouraged this persistence in the search for aggressive curative intervention. Ironically, this aggressiveness in seeking out treatment alternatives to offer patients coexisted with frequent observations and reports of staff discomfort about having contact with this population. Clearly, many factors, both positive and negative, are directing these ambivalent reactions of hospital-based personnel in their work with AIDS patients. Perhaps the intense suffering of AIDS patients, combined with their youth, drove many young health workers to vigorously apply the ideals of their professions to seek creative solutions to the therapeutic roadblocks they faced.

AIDS and the Disruption of Established Work Routines

Professional Work Routines

In order to care for their patients as well as conform to institutional needs for record keeping and documentation of their work, health professionals working on inpatient services rely on established routines to manage the complex and detailed tasks they must perform. Simple observations of such ordinary events of floor life such as giving a report or passing out medications to patients are all structured to conform to stringent government requirements and professional standards for care maintained by the institution. Routines for such apparently simple tasks as giving a patient a supplemental dose of a narcotic pain medication actually entail myriad detailed steps which must be taken to assure the quality of work and as a means of monitoring the intervention. A registered nurse must take the narcotic out of a special locked cabinet and sign it out in a special narcotics book in which the time, dose, prescribing physician, and patient name must be recorded. The usual medication book records must be filled in, and the syringe must be disposed of in special red "safe deposit" boxes to avoid accidental injury. Since nurses are legally responsible for the medications they give out to patients, they must assess the patients to assure they are not at risk of narcotic overdose. The

routines which structure these individual tasks rationalize and standardize work.

Staff attempts to revise routines that become disrupted by contingencies or problematic situations. AIDS generated many new problems for EEH staff which disrupted the existing order of work. Not only were the characteristics of the AIDS patients unfamiliar to many health workers but the characteristics of the illness were also initially unfamiliar. During this period of great uncertainty, established routines subsumed some of these problems which enabled staff to continue to function.

AIDS Impact on Work Routines

AIDS patients, particularly at the terminal stages of their illness, require unusual amounts of staff time to assure their proper care, which is particularly stressful where nursing and resources are limited. As expressed by a senior staff nurse:

> You really can't give the kind of care you want to give. So it's difficult. You have to set priorities about what is most important to be done. The day before yesterday, it was me on the one side with the nurse tech -- with twelve patients. So I had to do all the nursing care and she had to do all the patient care. It means beds were not done, a lot of things were not done. Your treatments, medications, and some assessments were done.

On this service, with nursing shortages and large numbers of AIDS patients, staff adapted by setting priorities for patient

care, similar to triage. The professional and nonprofessional workers decided on the essential tasks and then divided them. Cutting back to required tasks was a frequently observed revision of routine. Frequently, the tasks performed were chosen because they met administrative requirements for accountability, not necessarily patient care needs. Unfortunately, nurses felt that what they had to cut back to -- medications, basic care, and required paper work -- left them little time for more rewarding professional activities, such as patient education. Social workers might be contacted by patients, even though the physician was the appropriate resource. Social workers reported that they would clarify questions about medications because the physicians were unavailable to do so. From a practical standpoint, the social worker might have been the most accessible health worker because of house staff rotations and the fact that, unlike nurses, social workers give out cards imprinted with their extensions.

Besides the unusual body-care needs of this disease, other disease characteristics require innovative routines to manage behavioral problems. AIDS encephalopathy, resulting from the invasion of the HIV virus in the brain, was first officially recognized during the data collection phase of this study (Baines 1987). But even before studies confirmed the basis for mental status impairment among this population, staff had to manage these symptoms and their disruptive impact on floor life. One patient

accused a nurse of forgetting to hang his IV medications:

> He is a difficult patient to manage — at least to me. He was having short term memory loss. Like at nights, evidently something went on at evenings. He was supposed to receive a 12 a.m. medication and it never came up. The nurse told him it wasn't there but would be there at 2 a.m. The night nurse came in and he said, 'Where is my medication? I was supposed to get meds.' He started yelling and called the administrator on-call to complain. He kept this up all night. He denied that the medication was ever hung. When it comes to the fourth or fifth time in a night, you become rather irritated.

Loss of short-term memory can cause demanding behavior; in this case, repeated requests for medications which have already been dispensed. It also can precipitate conflicts among staff members. Health workers can be accused of forgetting important activities or patients can give different professionals different reports on their conditions because they can only report their present state. Once the problem is identified as a characteristic of the disease, the staff can develop routines for its management. First, the problem of memory loss can be addressed with the patient and then the staff can attribute the conflicting reports to the symptom, rather than to collegial or peer inadequacy. Thus, according to the same nurse, "We just had to keep telling him that because of the disease, he was forgetting. We all did it." Clearly, the fact that the staff can attribute the behavior to a disease symptom and therefore absolve the patient of responsibility makes the process easier.

Fears of Contagion

While fear of HIV transmission was a prominent concern of doctors, nurses, and social workers during the period of this study, as both media reports and scientific studies about AIDS transmission were reported, levels of concern about contagion waxed and waned. Many nurses, doctors, and social workers who had contact with the earliest AIDS cases did not take any special precautions. As an example, one physician told me that with the initial cases, procedures such as endoscopies were performed without eye protection, even though there was a risk of blood and other secretions entering the eye. As more information about AIDS became available, such risky behavior was replaced with hospital-mandated life safety routines. Moreover, as concerns about transmission intensified, some professionals developed their own routines to compensate for their deeper level of fear. The following example, reported by an attending physician, describes this process among new house staff working with an AIDS patient:

> When the new interns came here, I saw signs outside this door. It had "Respiratory Isolation." I said, "Why is this guy on Respiratory Isolation? I don't understand. Did something happen?" When he first came in they started sticking up all these RI signs and he had never had one before. So I said, "Why is he on Respiratory Isolation?" They said he had strep — that's a common organism. That's out there, I mean, it's not something he's going to give people. It's out in the community. It's just that you don't get it if you have a normal immune system. "Well," they said, "He's got PCP." I said, "Well, that's out there, too. We're all breathing it in. You don't get it it unless you have an altered immune

> system." They said, "Well, he had HTLV-III (HIV) infection. I go — "Well, as far as I know, it's not been spread to the wider community. It's just that they all come here, some from different things and they're so afraid of the disease that I think a lot of them just don't want to go into the room unless they have to. There are a lot of people in this hospital — the less time they have to spend with AIDS, the better off they are. The question is — How much can you let hysteria rule your life?

A social worker, who later reported her own anxiety about contact with AIDS patients, described the behavior of some nurses: "I have seen it happening in a number of staff. I would say, basically, with nursing staff they feel this way. Even in cases in which the patient is not in isolation, they will wear a mask and gowns and they will wear gloves — gloves are almost standard, because they have to deal with body waste. But they go through everything."

Routine protocols for contact with AIDS patients were published and to a limited extent available to staff through in-service training programs. Modeled on precautions that are taken with other infectious diseases, they are in some cases applied to protect the patient from infection, as well as to protect staff from being infected by the patient. Yet, while hospital workers cite staff training in this area, individual anxiety made precautions seem inadequate. In these circumstances, individuals developed private routines.

Problems of Identification: Affective Reactions and AIDS Patients

In earlier chapters, I described personal identification with the patient and patient expressions of gratitude as primary indicators of the ideal patient. In cases where patients offer little to satisfy health workers' needs, they can overcome their "toxic" status by expressing appreciation or exhibiting behavior which health professionals value. Heroism as a patient trait and devoted care as a family trait, at least where it conformed to staff routine, were highly prized. Patients who expressed gratitude were especially valued. This phenomenon is captured in the sentiments of a newly graduated staff nurse as she described a terminally ill cancer patient: "I didn't mind the fact that she needed so much of my time. She was always so grateful and the family kept telling me how thankful they were for what I was doing to help her. They were wonderful people. They reminded me of my own family." Obviously, the ability to evoke identification in the worker is another important indicator of patients identified as good.

Unlike the metastatic cancer patients described earlier, identification with AIDS patients was difficult for many health professionals observed and interviewed in this study. Since IV drug users were not a significant population at EEH, the vast majority of AIDS patients were bisexual and homosexual men,

although occasionally women and children were hospitalized with AIDS at EEH during this period. Although the urban dweller might be expected to be familiar with the existence of a large homosexual population in its midst, the intimate lives of homosexual men was unfamiliar and alien to most staff. Not unexpectedly, humor became a way of transmitting information about Gay sexual practices as well as dealing with the disquietude which these practices generated (Coser 1959). Jokes about Rock Hudson and homosexual activities were rampant during the study period. These jokes became a way of transmitting information about homosexual practices, as well as defusing anxiety about them.

Apart from exposure to gay sexual practices, health professionals confronted patterns of relationship and attitudes about health care which were also unfamiliar. These professionals had to account for life-style variations in their practices. For example, conflicts between lovers and family members or a family's ignorance of their son's sexual preference became common issues for social workers involved with these patients. Also, some AIDS patients distrusted traditional medical care and pursued non-traditional health practices, such as macrobiotic diets or stress reduction techniques in addition to, or in place of, more traditional therapies. Such behavior in a relatively young population conveyed more skepticism about the health care system and the status of physicians than generally observed in other

terminally ill patients. Moreover, these patients' awareness of staff homophobia exacerbated the problem of diminished trust.

Homophobic Reactions to AIDS Patients

The homophobic reactions described by Douglas et al. (1985). were observed among professionals in this study as well. One manifestation of homophobic response was the description of AIDS as a "self-inflicted" disease. A senior medical resident told me in an interview: "I didn't have much sympathy for these folks at first, until we started seeing AIDS in babies and women. That was different. But I saw it as a life-style disease. Self-inflicted." In another situation, an attending told me about his fellow in medicine who had become exasperated with an AIDS patient. She walked into the patient's room and said: "As far as I'm concerned, you're lucky you're even being treated here. You just brought this on yourself." This incident generated great administrative concern and resulted in the patient reporting the physician to a Gay Rights group monitoring patient care problems for AIDS patients. Apparently, individual values, even among the most highly trained professional groups, provoked negative reactions to AIDS patients. An attending physician with a large private practice in otology informed me that he was seen as "sympathetic," and therefore received many referrals of AIDS

patients. "Most of the guys here won't take them. Once they find out that you'll see them, you start to get a lot. I don't exactly love them either. But I think it's a part of what it means to be a doctor. I was trained like that." The telling part of this doctor's comments is, of course, his limited enthusiasm for this association, in spite of his apparently unusual capacity to overcome his reservations.

Homophobic reactions are tied to fears of contagion among some staff members. The excessive precautions taken by interns cited in a previous example demonstrate the level of concern among this group. Despite the advice of the attending physician who reported the incident that their precautions were exaggerated, the behavior persisted. A senior staff nurse said the following:

> It's like an air of prejudice. When you see an AIDS patient, it's "Oh, my goodness, it's an AIDS patient." I guess because there's so much talk about AIDS. What was it in TIME Magazine a few weeks ago. It was something about how almost anyone can get AIDS. AIDS is like the top of the list. Some of the people taking care of the patients really don't know any better. They figure they walk into a room to take care of a patient and they're going to get AIDS. If you take all the precautions you're supposed to take, you're not supposed to get it, according to the literature. But a lot of people are saying that if you really don't know what AIDS is all about, how can you tell me if I walk into a room, I won't get it. Like, these patients have a very difficult time getting private duty nurses. They even have a difficult time getting per diem nurses to take care of them.

Homophobia, uncertainty about the mode of transmission of AIDS, and its inevitable fatality combined to project a picture of aversive disease and patient characteristics.

The following observation illustrates the intensity of these reactions among physicians. In this example, the AIDS patient was an attending physician. Because he claimed that he contracted the disease through exposure to the virus while performing a proceure on an AIDS patient, he added to the anxiety of those physicians treating him, exacerbating their feelings of vulnerability. Apparently when doctors become patients, a conflict arises over which status, "patient" or "physician," is dominant. Here, the fact that the physicians at many levels of training and experience continued to suspect the validity of Dr. G's report confirms that the "patient" status predominated. Otherwise, the doctor's report would have been accepted by his colleagues as a matter of course:

> During rounds, Dr. L. and Dr. N. and I ran into Dr. H. Dr. L. asked Dr. H. if he had seen Dr. G. yet. He heard he was back in the hospital because his father had called about his drug. Dr. G. was also a surgical specialist who had AIDS. His wife, also a physician, had tested positive for HIV. Dr. G. had already been hospitalized many times because of the disease. He denied homosexual or bisexual activity or intravenous drug use. He claimed that he became infected when he performed a procedure on an AIDS patient and bloody secretions squirted into his unprotected eyue. Dr. H. said he had just been up to see Dr. G. Then he said, "You know, it's amazing. Every time some new intern goes to admit him, they go through the same thing. It says right there in the chart over and over again -- "denies homosexual or bisexual activity, denies IV drug use." And it's right there, the whole story about the blood squirting in his eye. And they don't stop badgering him -- "Are you sure you never...(mockingly) screwed a man?" They just don't want to believe that a doctor might have gotten AIDS taking care of a patient. It makes them nuts." Dr. L. said, "Of course, you'll never know the truth."

One physician, whose research involved frequent contact with

AIDS patients, developed some of the symptoms which he observed in his patients, notably dermatitis. Because of his concerns that he might have been infected, he anonymously sent his blood for HIV testing. This occurred twice over the course of this study. This physician did not belong to any risk group; and he knew that the possibility of HIV transmission through work related activity was minute, so his actions appeared excessive. A social worker also reported a single incident to me which precipitated intense anxiety on her part:

> We had this pre-AIDS patient and he was very anxious -- overflowing with anxiety and what-not. He used to get very emotional and, at some point, he spat and it hit my leg -- here. I said, "Oh God," and I couldn't wait until the interview was over. I rushed to the nurse's station and I took one of the cotton swabs and I wiped my leg. I thought to myself, "This is crazy.!" And then I started talking to one of the nurses and she said, "Oh no, it's not going to happen that way. You're not going to catch it." I said to her, "How do you know! Don't you hear all those things they are talking about?" When she reported the incident to me during the interview, the usually controlled social worker was breathless and spoke more rapidly than usual.

These illustrations indicate a high level of anxiety about transmission even among the most educated health-care professionals. The physician who repeatedly sent bloods for HIV testing was not only a health professional but, because his research involved AIDS, he was very well-informed about the limited risks of transmission for health workers. When I questioned him about this disparity between the extremely small possibility of his

having a positive blood test compared with his level of concern, he said that information was presently based on what could be ruled out, which as a scientist, did not mean "no-risk" to him. He also pointed out that of all the diseases you might acquire through occupational exposure, only AIDS was inevitably fatal.

The Impact of the Media on Health Professionals

The period during which I interviewed and observed health professionals was notable for virtually daily press reports on topics such as Rock Hudson's search for experimental treatment and ultimate death and the demonstrations of parents in Queens, New York, against admitting children with AIDS to public schools. Valenti and Anarella's finding that the media are a potent source of information for professional staff, even those with high levels of education, is confirmed by observations reported here (Valenti and Anarella 1986). Yet a subtle distinction should be drawn between the levels of information and levels of anxiety among this group and behaviors that complicate the care of AIDS patients in hospital. Knowledge does not seem adequate to contain anxiety about this illness, and there may have been panic because of latent fears of homosexuality (Nichols 1985). While it is beyond the scope of this study to address psychodynamic questions of terminal care, this question clearly deserves further attention.

Even in an atmosphere of fear and suspicion, individuals managed to overcome their aversion and performed their professional tasks, although the costs of these efforts could be great. In some instances, increased contact with AIDS patients compounded anxiety: for others, increased contact with AIDS patients modified aversive responses. Stability is important in becoming desensitizing to abnormal conditions. A head nurse made these observations about her staff:

> A lot of the patients are problematic. AIDS is still problematic with the staff. Although most people understand, a lot are still afraid. I haven't had any of my staff, to this point, refuse to go in to take care of them. They are still a little uncomfortable just handling them -- touching them. What usually happens is, when we get a new AIDS patient on the unit who we've never had before, it takes a long time for the staff to get involved with him. Once he's been here a week or two they get to know the patient, so it's not so bad.

Other researchers (Albrecht et al. 1982) similarly describe how stability allows people to predict the amount of disruption a stigmatizing condition will cause, allowing them to adapt to the disability. However, desensitization to one impaired individual does not necessarily carry over to others who are similarly afflicted, as the head nurse's observations about her staff indicated.

Research Issues and Clinical Practice with AIDS Patients

Much of the clinical practice with AIDS has been applied in conjunction with research protocols. Some comments about the relationship between these two streams of medical technology are important to understand care delivery for AIDS patients. For hospital staff involved in research projects, successful outcome is not necessarily focused on individual success but on the successful completion of the clinical trial. For many health professionals, specifically research nurses and doctors responsible for these studies, the work is organized along different dimensions; their work is a variation of clinical practice. Their view of patients may be different, too. Research protocols have been shown to interfere with decision-making about medical care for terminally ill patients (Stark and Johnson 1985). In one study, the specific needs of patients came into conflict with the goals of medical staff to provide clinical research opportunities in an academic medical setting. Another study described the way in which the constraints of research protocols limited decision-making opportunities for house staff-in-training in hospitals with large numbers of AIDS patients, since so many AIDS patients were involved in studies (Wachter 1986). Here, the patient's willingness to cooperate with treatment is not simply an issue for his individual therapy but affects the researchers' needs for cooperative research

subjects for the successful completion of their work. Good patients in this context are those who conform to the protocol requirements in a reliable and consistent way.

Two examples from this study convey the disjuncture between research requirements and patient needs. As reported by a medical social worker one patient's decision that the personal cost of pursuing treatment was not in his best interest frustrated the researcher who wanted to complete his work:

> This AIDS patient refused treatment. He decided that the best thing to do was to refuse treatment. He told Dr. X. that he didn't want to be treated for the infection and that doctor wanted that patient for his protocol. He got furious and said to me, "I'm going to kick his ass out of here." That man was really sick and we didn't have a place to send him.

In another case, a social worker reported the lack of involvement of physician researchers with patients on experimental drugs once the protocol had been completed "Unfortunately the minute a patient is discharged, the doctors tend not to follow up as much as one would hope. The patients get medication. I've seen a patient go home on experimental drugs for AIDS and the doctors say, 'Well, it's their problem getting it.' Here they are studying them and not even following them up." In this example, the researchers saw their primary work as research and did not extend their responsibility to clinical management of the research subject.

However, the limited enrollment of patients for trials of highly promising drugs can send both patients and their physicians to extreme means to find sources for such drugs outside the studies. During the course of this study, Op-Ed article by Matilde Krim in The New York Times (August 8, 1986) addressed some of the conflicts in withholding medications in the context of an inevitably fatal disease, another dimension of the conflict between clinical care and research for proving drugs efficacious and monitoring their side effects. Access to experimental medications for AIDS patients remains a critical health policy issue.

Technical advances can carry costs for patients, since biomedical successes can have negative as well as positive consequences. EEH-IMC was one of the sites for the multi-center study of Zidovudine (AZT). This drug was released before the study was completed because of its success in limiting PCP among AIDS patients. The response of the research team was complicated by their intense involvement with the patients in the study and by their knowledge of the side effects of this drug. The initial reaction was euphoria, but additional problems quickly dulled the enthusiasm of the team.

As a practical matter, one researcher wondered if the blood banks could keep pace with the need for blood transfusions generated by patients receiving AZT, since anemia is one of the prominent side effects of the highly toxic drug. According to one

of the group of researchers who performed these clinical trials patient-care consequences of AZT could get worse than care of patients who did not have the drug. The research teams are required to follow protocol patients until their deaths and, since the drug has been released from protocol requirements, to treat them with AZT if they wish. The drug clearly prolongs life for these patients but also protracts and complicates the illness trajectory for both the patients and the research team which must continue to provide care during its course. Because the side effects of AZT are severe even with reduced doses of drug, the costs in quality of life for patients, as well as the impact on the care givers and researchers, is profound. "It's actually worse, as far as I'm concerned, since you just have to care for them longer before they die." As described in an earlier chapter, technological advances redefine the illness trajectory; while the desired effects of increased life expectancy and fewer serious events are achieved, other consequences emerge that must be managed. Past routines may not serve the new circumstances, so new ones must be developed to assure the flow of work. Recent studies which indicate that AZT is successful in treating HIV infected patients (Massachusetts Medical Society 1989) leads to speculation that the trajectory of HIV infection may take the shape of chronic illness, such as diabetes, in future years.

Conclusion

This chapter examined health care worker's responses to a particular group of terminally ill patients, those with the Acquired Immune Deficiency Syndrome. The data provided evidence of the toxicity of AIDS patients, as well as the ways in which individual patients occasionally overcome this status. In spite of the toxicity of AIDS patients, these findings report incidents of dedicated and exemplary practice by some professionals, within a prevailing atmosphere of helplessness in treating AIDS and a persistent fear of both physical and psychological contagion.

CHAPTER SEVEN

UNDERSTANDING HEALTH PROFESSIONALS' RESPONSES TO DEATH WORK

Introduction

Many of the responses to the dying patients observed in this study appear to be paradoxical and distorted expressions of health professionals' stated missions and values. Behaviors such as avoiding terminally ill patients or passing them along to lower-status staff were frequently observed with these cases at EEH. In some instances, health professionals would become so involved in bureaucratic tasks that they ignored patient care. While these actions appeared to contradict the public image of acceptable professional behavior, as well as the stated value codes of professional groups, they allowed workers to tolerate routine problems presented by organizational contraints and pedestrian human limitations: they resolved the issue of failure for the person providing care.

In the face of the stresses of death work, these were not only individual responses, but sometimes became collective defense mechanisms which made the work bearable. Seen in this context, "social death" was not only a descriptive concept, it was a status

which allowed health professionals to detach themselves from their own ineffectiveness by dehumanizing those near physical death.

This chapter examines the patterns of responses of health professionals to death work, particularly as they are shaped by the disparity between the socially valued goals of professional health care and the lack of acceptable institutional and practical means to achieve those goals.

According to Merton's theory, when people are able to reach socially valued goals, they can conform to the usual socially approved methods of goal attainment (Merton 1968); when they cannot reach these goals, they experience anomie, or normlessness. In the case of contemporary hospital care, conformity is the pattern where correct technical intervention could be identified and applied in the service of the social good of "cure," with institutional supports to implement the curative technology. A simple example referred to earlier are the many cholycystectomies successfully performed for patients with inflamed gall bladders. All the technical and institutional requirements for success are present, including a favorable reimbursement under DRG's. With metastatic cancer and AIDS cases, on the other hand, we observe a lack of congruence between culturally prescribed aspirations and a socially structured means for achieving them. Not only is cure an unrealistic goal in these instances, but the tertiary care hospital is not structured to minister to the needs of the dying.

According to Merton (1968), contemporary American society is a culture which emphasizes success. In the face of repeated frustration of success, there are behavioral accommodations for those seeking to reach societal goals. These accommodations form the basis for a series of adaptations in response to anomie, or the normlessness experienced in the face of these failures. Innovation, ritualism, retreatism, and rebellion are the categories of behavioral responses defined by Merton. They will be used to describe the ways in which the EEH staff managed its problematic AIDS and metastatic cancer patients. After outlining Merton's typology of responses to anomie, I will review the responses of the health professionals reported in previous chapters in this study, comparing the unique reactions of the three professional groups studied and the institutional forces which determined them.

Merton's Theory of Anomie

In Social Theory and Social Structure, Merton (1968) presents a socio-structural theory of anomie which examines the relative disparity between the socially valued goals which people strive to achieve and the possibilities in the society for living up to those goals. In a culture such as ours, where success is an emphasized goal without equivalent emphasis on the institutional means for achievement, people face frustration in their efforts to succeed.

In spite of great pressure to conform or continue to strive in normative ways, the emphasis on success produces "deviant" responses as well -- or responses that are different from the generally accepted means available for achieving success. Deviant behavior is, therefore, a symptom of the gap between culturally prescribed aspirations and socially structured means for reaching them. In this way, the cultural values of the group may in fact produce behavior which is at odds with the mandates of the values themselves. Additionally, the goals themselves can be altered (Merton 1968).

Where congruence exists between goals and the means to achieve them, people are able to conform to expected behaviors. When they cannot, their behavior is modified. Merton presents four responses to anomic situations -- innovation, ritualism, retreatism, and rebellion. Their definitions are related to whether normative goals or means are accepted or rejected, or both (Merton 1968).

In _innovation_, institutional practices are rejected, but cultural goals are retained. The means employed to achieve the desired goals may be very effective, but they do not include the norms that govern the ways in which they are supposed to be obtained. With _ritualism_, the person abandons the cultural goals, but abides compulsively by institutional norms and practices. Bureaucratic virtuosity and over-compliance result when the situation creates anxiety about the capacity to measure up to

expectations. In retreatism, both the goals and practices are abandoned, resulting in avoidance and apathy. Rebellion leads people outside of the social structure to bring about modifications in the ways goals are achieved and may produce modifications of the goals themselves (Merton 1968).

As stated repeatedly by informants for this study, the primary goal for medical intervention in this institution was to cure patients, or barring that possibility, improve their functioning and return them well to the community. AIDS and metastatic cancer patients frustrated that goal and left health workers to struggle with repeated failure in the many cases that would not yield success in these terms. Seen in the context of the "deviant" responses outlined by Merton, behaviors that were antithetical to professional values can be understood as efforts to contend with this frustration. Health workers who avoided patients by limiting patient contact were practicing retreatism. Those who became absorbed in administrative details at the expense of direct patient care employed ritualism. Ritualism was also reported in work with AIDS patients where health professionals went through elaborate precautionary procedures when they were not warranted. When doctors advocated technology that clearly had no curative or palliative benefit, they were applying ritualism.

These "deviant" responses were not necessarily negative. In many instances, they could be described as positive solutions to

the anomie of death work in the hospital. Rebellion, for example, which in fact proved the most creative avenue in this schema, was evident when health workers revised their goals and tried to redefine the means for achieving those ends. The entire concept of the Supportive Care Service in fact was a form of collective rebellion, since the service not only changed the goal of cure to palliation, but altered the means as well, by advocating hospice methods of care.

Professional Responses to the Anomie of Terminal Care

In this study we have observed all three professional groups use a variety of strategies to deal with the anomie associated with the hopelessness of their efforts with the dying. While examples of innovation, ritualism, retreatism, and rebellion abound in all groups, some professional groups utilized certain strategies more than others. Structural work issues accounted for these variations to a great extent, since the work requirements and autonomy of the groups varied considerably. Also, nurses and doctors were more focused on the goal of curing patients, and they were consequently the most frustrated when their curative interventions failed. Social workers, on the other hand, were more able to find goal congruity between their work with the dying and provision of psychosocial support, so that their values and strivings were often

in accord.

Because doctors and nurses were more frustrated in their goal attainment with the dying, they were more likely to utilize retreatism and ritualism as responses. Additionally, doctors were observed to employ innovation as a strategy. Social workers were more likely to employ the goal redefinition available through rebellion, which was more available to them than to other groups by virtue of the wider range of goals available in their work and their relative autonomy. For nurses, work was more circumscribed by professional routines and a narrower definition of role. House staff could apply avoidance strategies more easily, particularly as they climbed the medical hierarchy. It is more acceptable for doctors than nurses to be off the floors and to avoid patients on their ward. Their interaction with patients can be purposefully abbreviated, while nurses would find such abbreviation difficult given greater demands to provide body care.

Responses of Nurses

Nurses have more intimate physical contact with patients than other professionals. Their work is more prescribed by administrative routines, and their day-to-day tasks are more closely monitored than doctors or social workers. Compared to nurses, social workers and doctors have more limited patient

contact, as well as more discretion in the amount of time they must spend with individual patients. Nurses' work is closely monitored and reporting systems for recording their work leave little room for creativity and circumvention of difficult situations. While avoidance strategies are available to nursing staff, their work is scrutinized and their opportunities for skirting problematic patients are fewer.

The pressure for administrative reporting funneled many of the anomic responses of nurses into ritualism. Bureaucratic rigidity, expressed in terms of strict adherence to nursing procedures, was a frequently observed response to difficult terminally ill patients. If nurses could not avoid their duties to patients, they could avoid dimensions of patient contact that were frustrating by seeking refuge in the demands of their routine. A widespread example of this phenomenon was the delay in administering rescue doses of narcotics to patients with metastatic cancer pain. Rescue doses can be requested by patients if their regularly scheduled doses are not adequate. Since the rescue doses were outside of the routine of usually dispensed medications, when patients requested extra pain medication, nurses responded slowly, citing the requirements to record narcotics in special books or the need to attend to other duties.

During the data collection period of this study, the nursing administration imposed stringent time utilization forms for staff

nurses. Nurses described the impact of expanding need for documentation of their work. When approached about participation of her staff in this study, one head nurse said that without administrative approval, she was afraid to release her nurses for interviews, since it would represent undocumented time for her staff. Within this atmosphere, nurses relied heavily on the expanding need to complete forms as a way of explaining their limited interaction with problem cases. Paradoxically, the stringent reporting requirements to both funding bodies and the EEH nursing administration intended to ensure quality treatment intensified problems with difficult dying patients who frequently demanded extra nursing time. This situation inhibited the capacity of many staff nurses to apply positive and creative solutions in managing toxic patients.

Ritualism was the way in which nursing administration handled the problem of understaffed floors and represented a collective defense mechanism against a failure of both successful goal attainment and appropriate means to achieve success. Particularly on floors with large numbers of AIDS patients, nursing staff was often inadequate to meet their acute needs. The administration had a system for assigning increased coverage on such floors by requiring the head nurses to document the seriousness of patient needs and manpower availability using a point system. Nurses complained, however, that when their forms were submitted, they

were often told that while they indeed warranted more nurses, no nurses were available to be deployed to their floors. The system clearly thwarted success in providing very sick patients with quality patient care, but it represented an institutionalized version of ritualism that accounted for a process without achieving the goal of increasing floor nursing staff.

One way in which nurses practiced retreatism with dying patients was to utilize specialized staff. When faced with problems with dying patients, nurses would call in "death talkers," Quint's expression for hospital personnel designated by the hospital for managing dying patients (Quint 1972). Rather than handle problems on their own, they deferred problems to other staff. Although in one sense this delegation to other qualified staff was appropriate, it enabled nurses to avoid contact with unpleasant, difficult cases. The SCS nurse coordinator, who was available to medical and surgical nurses for consultation, also served the role of "death talker." She not only met with nursing staff to advise about clinical and psychological aspects of terminal care, but she followed a number of metastatic cancer patients in the process of defusing the emotionally taxing aspects of other staff members in caring for these patients. The hospital chaplains were also called in as "death talkers," a service which was probably underutilized and could have provided relief for nurses, as well as spiritual support for the dying patient and

family. Religious intervention was not always comfortably received by staff members.

Rebellion, redefining both goals and means, as a nursing strategy, was primarily the purview of head nurses. Some head nurses were able to develop independent solutions for their staff or would openly challenge institutional practices that clearly had a negative impact on patient care or staff stress levels. A continuous problem for these middle management personnel was the relative youth and inexperience of their staff nurses, as well as what they perceived of as a serious problem in staff turnover. During the course of this study, the nursing administration issued a report that staff turnover had decreased in the department, yet the head nurses frequently described turnover as a problem in managing the floors. It was a particularly acute problem for them, since the head nurses were responsible for training and integrating new staff.

For those head nurses who looked upon training as an opportunity to provide support strategies, particularly around terminal care, the process resulted in an acculturation of floor values which encouraged a positive view of the role of nursing in terminal care. The one head nurse who described her floor as a "oncology service" paradoxically also had the most optimistic and content staff observed. Conceptually, by stating that what the nurses were actually doing was death work, she collectively

redefined the goal of their work for the nurses on this service. They were then able to conform to institutional norms that operated in the service of attaining those goals. With this broader view of their function, nurses on this medical floor were in fact able to carry out their work in ways that enabled a successful outcome.

Responses of Attendings and House Staff

The autonomous nature of medical practice, even in an environment of expanding regulation, gave license to innovation, retreatism, and rebellion as primary strategies for doctors to manage troublesome dying patients. Ritualism was frequently utilized, as well. Occasionally, ritualism was seen among house officers who focused rigidly on the medical management of patients. Ritualism was also observed when physicians pursued futile technologies in the terminal stages of a disease without any real expectation of their success. While the goal of cure or even protracting the patient's life was clearly beyond reach, some practitioners continued the pursuit of a phantom goal. This persistent although hopeless pursuit clearly served the socio-structural needs of the institution and not necessarily the good of the patient or family.

A particularly perverse example of ritualism presented earlier in this study was the physician who retaliated against a patient

who refused to go along with his recommendation for treatment by calling the Utilization Review nurse to review the patient's case. The attending insisted that the bureaucratic requirement be applied in a way that did not benefit the patient. In fact, it added emotional stress for the family very near the time of the patient's death.

Attendings along with house officers were observed using a number of retreatist strategies. The sparse and infrequent chart notations on dying patients noted in a review of SCS patient charts as these patients approached death is trace evidence of how effectively physicians avoided the dying. According to observations and reports from medical informants, rounds and patient visits for terminally ill patients were frequently abbreviated.

A good example of rebellion negatively applied was when doctors would accuse pain patients of drug-seeking behavior or of being overly demanding of the doctor's time. In the instance where an SCS patient was placed on a palliator pump and self-administered doses of Dilaudid, her persistent pain, dementia, and anger led the house staff to frequent informal dump sessions where this patient became the object of particularly vehement verbal attacks. When this form of rebellion moved from back-stage to on-stage, as in the case of several public condemnations of AIDS patients by physicians, the professional value system was severely

compromised. Much of the backstage behavior observed during this study indicated a similar attenuation of expected professional values.

In some instances, doctors were able to bridge the disparity between their curative ideal and the palliative needs of terminally ill patients. They could substitute psychological and physical comfort as the desired goal, and also locate appropriate, though "deviant," means for that end. While this position was not always supported by the institution, creative efforts could produce successful results for some patients. By redefining the goals and means for managing these patients, they were practicing a positive form of rebellion, positive in the sense that it enhanced patient care and conformed to professional value systems.

Certain physicians assumed this role institutionally, either because they were perceived of as good care givers to the dying by other professionals, or because they actively pursued this professional tangent. The SCS doctors, riding the crest of the hospice movement, capitalized on what they saw as the need to train medical staff in methods of palliative care. Although they were successful in getting referrals, particularly of patients who were management problems to other staff or patients with discrete problems in pain management, their efforts were less successful in influencing their colleagues than attending oncologists who managed patients throughout their illness and were then able to redefine

their efforts as "palliative" when patients approached death. One oncologist was an especially adept teacher in this regard, and her credibility as a "good doc" enhanced her ability to influence younger doctors. In general, the oncologists had more power than the SCS doctors and could bring to bear more institutional resources for the benefit of patients.

Responses of Social Workers

As described previously, for social workers, the ideal of patient cure is not central to their work in the way it is for doctors and nurses. Their institutional role does not directly involve curative functions: rather, their function is to locate community resources and arrange for discharge for patients. These tasks are essentially the same for patients whether they are terminally ill or not. But, in general, resources for the terminally ill were accessible, and the routines for planning after care were in place. Problems arose when there were barriers to after-care planning, as in the case for patients with AIDS, since resources at that time were unavailable. Social workers were frequently frustrated in their attempts to locate community resources for their AIDS patients.

When faced with lack of resources, social workers could employ a form of ritualism. From a practical point of view, their

responsibilities to the institution were met when they could document filing referral forms for clients to appropriate after-care facilities or programs. From the perspective of hospital reimbursement, noting these activities in the patient chart was sufficient. Even if the goal of after-care placement was never achieved, the institutional expectation was met.

Social workers could wait out the process, which included waiting for the patient to die. By necessity, social workers became proficient at putting off questions and demands of house staff and nurses. For them, patients who were ready for discharge but who remained on the floors easily became defined as "toxic." New house officers would persistently question the retention of patients who no longer required acute care hospitalization. In Mizrahi's terms, these patients were undesirable because they did not meet the educational needs of house staff. Consequently, hard-to-place patients were "GROPed" to the lower status social work staff (Mizrahi 1986). However, some social workers saw their role in relation to house staff as educative. They extended their work responsibilities to include informing new house officers about the discharge needs of patients and psychosocial issues in after care. This represented rebellion in redefining the goals and the means for their achievement in a broader context.

In fact, this study uncovered many highly original ways that constituted rebellion or innovation, in which social workers

contended with problematic dying patients. When workers redefined how they might intervene with a problem situation, they produced some of the most innovative and productive work reported in this study. The social worker who extended her role to include counseling the wives of deceased cancer patients when there was no institutional support for such work is one example. This involved reconceptualized and broadened the scope of the work to include ongoing supportive counseling or bereavement counseling.

Several examples of rebellion as a positive solution were observed in this study. The social worker who described the patient with cancer of the penis as toxic because of the identification of young house officers with such a threatening diagnosis responded by organizing a staff support seminar to address this issue. Another example was the social worker who was able to defuse the hostility of the patient's wife who barred staff from her husband's room with offensive signs. Excellent social work practice in a frustrating situation for all professional staff enabled the worker to develop a supportive relationship with this patient's wife, and ultimately gave other health workers greater access to the patient. In fact, where other professional groups retreated by avoiding patient contact where they could, social workers increased contact with dying patients, and they defined their role as providing psychosocial support. The worker who described her daily sessions with a young AIDS patient waiting for

discharge when no placement was available is another example. While medical staff no longer saw these patients as opportunities for success, social workers did. These examples, where social workers stepped out of their institutionally defined role as discharge planners, eased the work for other professional staff and supported their capacity to render care in difficult situations. They also enhanced the care of patients who otherwise would have clearly been avoided by most professional groups.

The success social workers felt in relation to their work with the dying sustained them in the face of their general frustration with their position in the hierarchy of EEH. The fact that social workers were able to capitalize on the frustration of others in work with the dying points to an important focus for social work intervention in hospital systems. Even though that function is not necessarily supported by the institution or defined by other professional groups, it is a professional function consistent with the education and value base of good social work practice. Social work staff and administration need to step up the institutional perception of the mediating function of social work in regard to the dying and to difficult patients generally. Such recognition would not only support individuals faced with frustrating and difficult work, but would enhance the in house value of this often maligned professional group.

The Supportive Care Service as Rebellion

The Supportive Care Service was an organized effort to challenge the way in which dying patients were cared for at EEH, and to offer an alternative technology and system for serving these patients in the context of an acute care hospital. As such, the SCS represented a response to the anomie of treating the dying in tertiary care hospitals with a collective form of rebellion. The service aimed at sensitizing all professional groups in the hospital to a vision that was unique to this setting and shared little with the ordinary value structure of the hospital as a whole. By advocating palliation instead of cure as an important goal, and suggesting as means low-tech interventions, such as laxatives and "sips and chips" in an institution which thrived on technological advancement, the SCS represented a core of rebellion at EEH.

While the SCS clearly made a difference in the care of the patients it followed, its isolation from the normative strivings of the institution as a whole severely limited its capacity to change the system in any enduring way. Instead, other professionals criticized the service for its lack of realism in the face of the routine demands of institutional life. For example, nurses and doctors complained that many of the medication regimes suggested by the service did not account for the time pressures of the nursing

staff who were supposed to implement them. Clearly, few attending physicians or house officers could afford to spend the time with patients and their families that was available to the SCS medical staff. House staff and attendings saw the SCS doctors as unrealistic.

The limited success of the SCS to influence the mainstream doctors at SCS can perhaps be understood in this context. Because they discarded and in fact ignored the pressure to conform in the hospital, they appeared arrogant to the physicians in control, and therefore lost their base of support. The nurses and social workers who benefited in more direct ways from their efforts, and for whom there were no questions of competition for patients, did not have adequate power at EEH to sustain the service.

Conclusion

While the whole repertoire of anomic responses was observed among all professional groups, two important observations can be distilled from this analysis: First, professionals who were able to redefine goals and were creative in developing unconventional strategies to manage difficult problems with dying patients were positive and optimistic in reporting their efforts to this investigator. They were able to view these outcomes as successful. In this way, they sustained their creativity and conformed to the

mandates of their professional values in a clear way.

Second, social workers were in general less constrained by their institutional work definitions and were able to define failed cases by the standards of other staff as successful by their own. Thus, for example, embittered and confused wives of deceased cancer patients were helped to manage the financial consequences of their newfound widowhood. Problematic patients and their families were made tractable by good social work intervention. AIDS patients waiting in hospital for limited community resources were given ongoing supportive counseling. These positive interventions not only served the workers, but also the patient, the patient's family, and the hospital.

Understanding the failure of the SCS to have a sustained and enduring impact on the operations of EEH can be seen as an example of unsuccessful rebellion. Since the strivings and methods of the service were so outside of normative EEH goals and practices, it remained isolated from the organization as a whole.

CHAPTER EIGHT

CONCLUSION AND PRACTICE IMPLICATIONS

Introduction

Renee Fox (1985) observed the dearth of sociological investigation into the individual and collective defense mechanisms used by professional health workers as they respond to life, death, and suffering. How health workers come to grips with these powerful events can effect both the technical and humane application of professional skills. This exploratory study of the responses of doctors, nurses, and social workers to death work is an effort to uncover clues about how health professionals define this work and to understand the ways in which they cope with their work with the dying. The utility of such a study is to develop strategies for supporting the work of health professionals with dying patients and consequently to make more humane the level of care they receive. Particularly within the context of increasing cancer morbidity and the appearance of AIDS as a new illness, the ability of workers to care for the dying is a problem of considerable social importance.

In this concluding chapter, I will review the study methods, the context in which the study was undertaken, and some of the significant findings from this study. I will draw comparisons between the responses of professional care givers to metastatic cancer patients compared to AIDS patients, as well as differences among the three professional groups of health workers in their responses to terminally ill patients in general. My discussion of the implications of this study for hospital practice with dying patients will focus on ways to support the work of professional care givers to the dying. I will also describe problems anticipated in the care of AIDS patients as the epidemic has developed since the study was undertaken.

Review of the Study

The methods used in this study were drawn from "grounded theory," (Glaser and Strauss 1967) and consisted of participant observation and focused interviews with professional staff, specifically doctors, medical nurses, and social workers, about dying patients from their practice whom they found "difficult to manage." Fifteen patients were suggested for the study, six of whom had AIDS, and nine of whom had metastatic cancer. In total, eight physicians, ten nurses, and thirteen social workers were formally interviewed about problem patients. All of the patients

were considered "hopeless cases," and were fully expected to die within six months.

Based on an analysis of recorded observations made during my association with the Supportive Care Service and interviews with doctors, nurses, and social workers about dying patients in their care, I developed a typology which describes three terminally ill patient types in relation to the needs of professionals for cure or symptom amelioration, routinized work, and personal gratification. "Ideal" patients responded beyond what was usual to treatment or had personal characteristics which engaged the altruistic motivations of health workers. "Routine" patients conformed to normative expectations and presented routine problems for staff. "Toxic" patients disrupted hospital routines, had unattractive personal characteristics, or questioned professional authority. Certain disease characteristics, such as intractable pain, could make a patient toxic because they would disrupt ordinary work routines. This typology was used as a basis for analyzing the observations and interview material collected in this study. It provided a map for understanding how health professionals categorized terminally ill patients as good, routine, or extremely difficult to manage.

If the goal of professional health workers in acute care hospitals is to cure patients and send them home to productive lives, many forces — progress of medical technology, the health

system, the psychosocial problems of individual patients and their families, and most significantly the fact that human life is finite — can thwart this goal. The methods used in this study were chosen to capture the perspective of professional health workers and describe from their own points of view their efforts to contend with the frustrations of this dilemma.

The study was undertaken during a period of rapid change in the context of health care and in the face of AIDS, a new disease which profoundly questioned the technical invincibility of modern medicine in response to disease. This situation underscored the problem faced by health workers, that is the frustration of managing patients for whom there is no cure in an institution where cure is the paramount goal. Additionally, the anticipated introduction of DRGs was seen as an additional constraint on autonomous practice, particularly problematic for the care of very sick patients. It accentuated institutional forces for a success oriented perspective for acute care hospitals.

It was in this context of rapid change that I was able to examine health professionals' strategies for handling death in established medical systems. Using Merton's (1968) theory of anomie and his formulation of categories of responses to situations where successful goal achievement is thwarted, I was able to compare the ways in which the various professional groups managed their goal frustration using innovation, retreatism,

ritualism, or rebellion, noting that some modes of responses were more typical of each professional group, and that responses could be applied both negative and positively.

Changes in Terminal Care

It is clear from this study that many of the problems articulated about terminal care in this country beginning in the 1960's remain entrenched the health care system. It is also evident that much has changed. Some changes have been prodded along by advancing treatment technologies. When curative measures are available, patients need to know that they can elect or reject them. The vignette reported earlier where the daughter is relieved that her mother is ineligible for chemotherapy because she will not have to be told she has cancer makes the situation immediately understandable. It is no longer easily possible to treat cancer patients without their understanding and cooperation with treatment plans, even if family members want the information kept from the patient. Similarly the civil rights concerns about HIV testing when there was no effective medical intervention are quickly eroding in the face of evidence that Zidovudine (AZT) can be used to delay bouts of Pneumocystis carinii pneumonia (PCP) in people who are HIV positive. Closed awareness, as described by Glaser and Strauss (1969) is no longer the norm, in part because of this

structural dimension in care giving and in part because of the impact of the messages of the death awareness movement. At the very least, early advocates of the importance of disclosure to very sick patients gave health professionals a way to approach the issue with their patients.

Other important changes have come about because of the infiltration of concepts from the hospice movement into the mainstream of medicine. Whether or not the whole system has been converted, certain more humane methods for caring for the dying are accepted in traditional treatment settings which in the past would have been denied patients. The most apparent is the acceptance of adequate administration of narcotic medication for the control of pain in metastatic cancer patients. This change has no doubt been supported by the increased ease of management when patients are kept comfortable. Even here, however, many health professionals, particularly nurses who are responsible for the medications they give patients, remain concerned about respiratory suppression and addiction when they give narcotics around the clock and not simply when patients request them.

Other hospice concepts have not been integrated into the acute care system. For example, extensive use of volunteers for providing support for patients and family have not been utilized in acute care settings. Also, an increase in the authority of nurses in the decision making in terminal care is not evident. Obviously,

the abandonment of curative treatment with terminal cases is not practiced in these institutions, perhaps because there is a self selection process where "fighters" are more prone to seek tertiary care than "settlers" are. Additionally, patients who refuse or are ineligible for acute care will be discharged under DRGs and utilization review procedures.

For the most part, aside from specific palliative treatments, hospice concepts are not easily utilized in hospitals. Institutional forces that are necessary to preserve the integrity of the acute care hospital regarding regulations and standards of practice do not allow for their implementation. Whether hospice care can become a viable alternative for the dying is questionable, since health care in this country is so predicated on success and technological application. The underutilization of hospice care by eligible Medicare patients bears out this point (Lukashok 1987).

Comparing the Death Work of Doctors, Nurses, and Social Workers

Informants in this study came from three professional groups working in hospital -- doctors, nurses, and social workers. Comparisons among these groups in relation to terminal care emerge both in terms of the types of strategies which different professional groups use to cope with their work and in the degree of congruence between professional objectives and the nature of

terminal care. Clearly, the hospice movement pointed out that the physician should serve a consultative role in terminal care, and that nursing offered the most productive discipline to accomplish comfort care strategies. But, as noted earlier, in acute care hospitals, the doctor is still the dominant professional, so that nursing's position may not be adequately powerful to gain ascendency. Social workers on the other hand find considerable professional congruence with supportive interventions with dying patients, and appeared the most satisfied in this work, institutional requirements for discharge planning notwithstanding.

This study indicated that social work intervention had a positive impact with both metastatic cancer patients and AIDS patients, as well as for the other professional groups providing their care. Yet this work often remained unrecognized by other professional groups. Social workers were observed to be poor advocates for their roles. Social workers in this study behaved as if they had a "guest" status in this hospital and operated as if their work was at the behest of the physicians, particularly attendings. They frequently approached their interventions in round about ways or else waited for other professionals to refer patients. Although social workers were able to articulate their impact in a clear and purposeful way to me during interviews, I did not observe them interpreting their work to other staff members.

Professionals used a variety of strategies to contend with the

socio-structural anomie generated by their encounters with the dying, which I have organized in the four responses proposed by Merton (1968). Innovation, ritualism, retreatism, and rebellion are the ways in which people manage barriers to the achievement of socially valued goals. Doctors were the most frustrated when their curative interventions failed. Because they were able to work in a relatively autonomous way and they had considerable discretion over how they allocated their work time, they were able to retreat from difficult situations by avoiding them. They could also manage problems by referring to bureaucratic regulations, thus placing the responsibility for their actions on hospital rules. The attending who requested utilization review for his patient was applying a ritualistic solution to manage his frustration with an intractable family member.

Nurses had the most direct contact with very sick patients, and they had the least control over the allocation of their time. Their work was closely monitored by the supervisory staff on the floors and ultimately by the nursing administration. Nurses, therefore had fewer opportunities to avoid problematic situations than either doctors and social workers. However, because their work required significant amounts of administrative record keeping and reporting, nurses utilized ritualism as a response to difficulties with the dying. When head nurses employed rebellion and redefined the goals of their staff as treating malignant

disease, nurses were more satisfied with their work.

Social workers were able to find more goal congruity between their work with the dying and provision of psychosocial support than the other two professional groups. When they broadened their roles beyond the institutional needs, but not professional mandates, they used a positive form of rebellion to convert their frustration into a positive outcome for very sick patients. Clearly, social workers had opportunity to retreat from problem situations, or at least limit contact with difficult patients and families, since their work schedule was very autonomous. They could also bring to bear bureaucratic rules and regulations to handle difficulties.

Comparing Professional Work with AIDS Patients and Metastatic Cancer Patients

First identified in 1981, AIDS, unlike advanced cancer is a disease without a history, and with which health workers working during the period of this study had virtually no antecedent experience. Working with cancer patients for the most part presented familiar, routine, and predictable problems. Even given the explosion of chemotherapeutic treatment in recent decades, therapeutic regimes and consequently work and referral patterns are well established. The lack of such routines to structure and

direct the work of professionals made AIDS patients as a group more problematic than metastatic cancer patients. It is perhaps this fact that propelled numbers of staff working with AIDS patients to explore the limits of their interventions in relentless searches for community resources or drug trials in which patients could enroll. When the routines are more predictable, workers are more likely to follow a ritualistic tack. With AIDS patients, however, the lack of routine contributed to the stress experienced in doing this work because it provided no measure of worker accomplishment, and it removed the ordinary definition of the work experience for many professionals. Additionally the fact that knowledge about AIDS was rapidly evolving and consequently non-routine and unstable even for professionals working with AIDS patients fed this process.

AIDS patients and patients with metastatic cancer are seen by health workers as dying patients. Although medical interventions may be available to these patients which serve either palliative functions or to prolong the lives of patients, they are tied into progressive, linear illness trajectory with death as the end point. With the first opportunistic infection with which a patient is diagnosed with AIDS, they are seen as dying. Even if the initial indication of disease is a small Kaposi's Sarcoma lesion, the health worker sees the patient moving on a course towards death.

During the period in which this study was undertaken, there was very little experience with the treatment of AIDS. This clearly

framed the cancer and the AIDS trajectories in different terms, since with a diagnosis of AIDS, unlike a diagnosis of many cancers, expectations about the course of the disease were not established. Professionals felt nothing could be done, or what was in fact done was only seen as delaying the inevitable. Even in the presence of metastatic disease, the remarkable cure or remission is occasionally described. During the period of this study, the most overriding feature of AIDS, and its most distinctive characteristic is that it was seen to end in the patient's death. For health workers working in the interventionist context of the acute care hospital, this characteristic was highly problematic and not productive to work satisfaction.

A most serious difference for care givers in caring for metastatic cancer patients as opposed to AIDS patients was the question of contagion. Hospital personnel are not afraid of contracting cancer while providing care to sick patients. With AIDS, however, many health workers did fear that they might contract AIDS in the course of their work. While epidemiological studies, including the monitoring of all reported occupational accidents with AIDS patients and their bodily fluids, never indicated extreme risk, health professionals were frightened by news reports and by the fact that information about this disease was ever-changing. Anxiety was heightened around the period during which informants were interviewed for this study. News reports

about the disease were widespread and focused on sensational events, such as Rock Hudson's pursuit of cures for AIDS and ultimately his death. As discussed earlier, health workers got most of their information about AIDS from the media (Valenti and Anarella 1986), and the anxiety projected in television and newspaper coverage extended to health professionals as well as the general population. Eventually, the Center for Disease Control (May 22, 1987) reported transmission of HIV infection to health workers through contact with infected blood which clarified the possibility, although remote, that health workers were at risk.

As noted earlier, AIDS has occurred within specific populations in society, primarily among gay men and IV drug users, although at EEH during the period of this study, the AIDS patients were primarily gay men. Besides the fact that these patients come from stigmatized groups in our society, they also brought life style variants to a mainstream and traditional hospital community which was at odds with the hierarchical and authoritarian dimensions of its culture. Metastatic cancer patients, on the other hand, come from all social groups and as observed here appeared for the most part to accept professional authority to a greater extent than AIDS patients. Of course, when they did not, they were soon identified as "toxic" by staff.

For example, an important issue that undermined the acceptance of professional authority was the use of alternative therapies for

treatment. Patients who pursued alternative therapies were frequently labeled "toxic," particularly if they refused traditional treatment in the process. Many of the AIDS patients at EEH who came from the culture of the urban gay community used diet and stress reduction therapies in combatting AIDS. When the pursuit of these therapies questioned professional authority or interfered with the routine production of work, it earned patients a "toxic" label.

Additionally, metastatic cancer patients include a familiar range of family types, and individual patients would be more likely to have family constellations which would be familiar to staff. Gay men, on the other hand might have lovers or estranged parents or significant others participating in their care which would not represent familiar family groupings to health workers.

In a more general way, the development of the Gay community in the past two decades has evolved a distinct culture, where Gay Pride and political activism played significant roles. While this movement allowed for the development of advocacy and self help programs to deal with the AIDS epidemic, it also has produced antiauthoritarian and angry sentiment among many Gays. In the face of a new disease which has felled so many in this community, it is no wonder that the considerable anger is directed at institutions which do not support this culture and which in general do not embrace a Gay lifestyle.

This conflict and the homophobic responses of many staff to homosexuals in their care led to monitoring of health professional behavior by Gay activist organizations. In some instances health workers were faced with conflicts between professional and religious values for which they received little direction in resolving. For staff who held beliefs that categorized homosexual activity as immoral, the integration of personal and professional values could be severely tested.

Clearly the relative youth of AIDS patients as compared with cancer patients made work with these patients more difficult for staff. Young metastatic cancer patients are also problematic for staff, but such patients are seen only occasionally. The appearance of so many young patients facing death, particularly where the physical and intellectual transformation of the patients was so profound caused great anxiety on the part of staff.

Recent Developments in the AIDS Epidemic

Rapid developments in the AIDS epidemic, both in epidemiology and treatment, have already begun to shape the way in which health professionals view this work. The use of AZT and Pentamidine as prophylaxis against PCP for people with full blown AIDS, as well as HIV infected individuals gives health professionals a specific therapy which adds a dimension of hope not previously available.

Clearly beneficial therapies help health professionals feel more effective, and as new therapies develop will encourage some optimism for the health provider community. Along with improved therapies, the work for professional care givers will become more routinized and predictable.

While this study was undertaken in a hospital where the majority of AIDS patients were Gay men, IV drug users already made up a significant proportion of HIV infected individuals. Presently, the focus of the epidemic is shifting to the point where IV drug users are the majority of new AIDS cases reported.

The problems for hospital workers treating Gay men with AIDS have been described here. Problems in hospitals managing large numbers of IV drug users are even more complex, given a number of factors. If patients can be blamed for life style factors which put them at risk for disease (Fox 1986), IV drug use, already viewed as undermining the health of the addict, is an even more destructive activity.

Intraveneous drug users often utilize health care systems in maladaptive ways, which, based on the observations in this study, health professionals would categorize as "toxic." Reports of addicts signing themselves out of the hospital against medical advice or refusing recommendations for procedures or treatment are examples. Additionally, the social problems of drug addicts can overwhelm the health worker, at the same time patients make

decisions on the basis of values antithetical to the professional. Heagarty in calling for more humane care of these patients says, "these impoverished drug addicts...are often antisocial, rude, and angry. They can be infuriating when they don't take care of themselves, don't follow our instructions, and fail to return to the clinic on schedule or take their medications" (Heagarty 1987, 114). Confronted with this litany of "toxic" attributes, providing humane and compassionate care will present a challenge, particularly in an environment of limited resources.

Strategies for Supporting the Work of Professional Care Givers to the Dying

Death work does not fit easily into the overall structure for care giving in the modern medical complex, and even where professionals have been able to routinize their work with the dying, it still carries the cost of failure by institutional definition. This price is often paid by patients and families at a point where humane care, and the technologies available for its application, may be the most important purchase they could make. Work with dying patients is difficult for health professionals, and even more difficult with patients and families who pose special problems for health workers. Lack of institutional support for time spent in caring for these patients, as well as the confrontation with mortality such work entails add to the

difficulties.

In spite of the "toxic" nature of death work generally, some of the work observed in this study revealed professional success and exceptional resourcefulness on the part of individual professionals. Although some of these efforts were aimed at institutional change, such as the work initiated by the SCS, individual doctors, nurses, and social workers through their own personal ingenuity were able to provide excellent care for the most intractable patients. The lessons to be learned from their creative efforts are the basis of recommendations for supporting the work of those who face similar problematic situations with the dying.

While broader efforts directed at systematic change might seem an appropriate suggestion, the counterfailing forces against such efforts are considerable and have little direct impact at the point of care delivery at the patient/professional interaction. Also, the forces for retaining the system as it stands, especially patterns of third party reimbursement and investment in biomedical scientific development, call into question any effective method for altering the direct of care for terminally ill patients while they are hospitalized. One can reflect on the fate of the hospice movement and the present underutilization of Medicare reimbursement for these services. As described in this study, the SCS was unable to sustain itself as a countercultural service in the EEH

environment. Services which are not institutionally meshed may also have limited longevity or impact. Efforts aimed at individuals or groups more closely woven into hospital life would be more productive.

The best possibility for improving the humane level of care for the dying rests in helping professions develop adaptive strategies for their work with dying patients. In the past, these efforts have meant teaching doctors, nurses, and social workers about the psychological and social response to dying or stress management techniques. Developing more productive strategies for handling problem cases, or at least a forum for their resolution would be more beneficial. While this does involve administrative recognition of a particular staff issue, it is an educational strategy which can be incorporated into existing staff development formats, perhaps using didactic techniques which would involve improving the skills of middle management personnel such as social work supervisors residents or head nurses.

Returning to Merton's formulation, when professional groups or individuals were able to employ positive expressions of the "deviant" anomic responses, they were more productive and could derive satisfaction from some measure of success when confronted with the socio-structural anomie generated by their work with the dying. Success in this regard requires redefinition. Here it means that the professional will be able to improve a "toxic"

situation, both in terms of a personal sense of accomplishment and by delivering better care to patients. This involves a set of skills which can be analyzed and taught.

Using Merton's concept of anomie as the basis for a curriculum for teaching supervisory personnel is a reasonable next step for a practical application of the findings of this study. Teaching examples from all of Merton's categories are available here and might be applied in such an effort. A small model project involving hospital professionals could be tested for its impact on staff work with the dying.

Areas for Further Study

It is beyond the scope of this study to propose and test teaching models for health professionals aimed at improved care for the dying. However, this study does provide suggestions about how health workers handle "toxic" situations in both productive and unproductive ways. This can serve as the basis for curriculum development in this area. For example, the social workers in this study did not have effective means to communicate their role in the hospital. Training could focus on developing assertive techniques to project the mediating role they actually perform. Or, trainings for head nurses on medical services could help these middle management personnel reconceptualize the work they do, and develop

in-service trainings to support the work actually performed. Clearly, the development, implementation, and evaluation of training efforts are called for, particularly in light of the enormous burden which professionals can anticipate in caring for IV drug users, their sexual partners, and children diagnosed with AIDS. Successful in-service education efforts about AIDS with hospital workers have been widely reported (O'Donnell and O'Donnell 1983 and Wertz et al. 1987) although further efforts are called for, particularly in light of dramatic changes in both treatment and the population infected.

This study was undertaken in a single institution, using methods designed to organize and clarify the impressions of health professions about a serious issue in health care. The findings are only suggestive, but point to a number of questions which merit further investigation. Most obviously studies of health worker responses to treating drug abusing HIV infected patients is critical to understanding how these interactions might be improved. Since EEH is an elite institution, and not representative of the broader hospital community, comparative studies of the care of the dying in other institutions could reveal intrainstitutional factors which enhance or detract from humane patient care.

Conclusion

This chapter summarized the major findings of a qualitative study of the responses of health professionals to their work with terminally ill patients in hospital. The study focused on reactions to work with problematic or "toxic" dying patients and the ways in which doctors, nurses, and social workers managed, both successfully and unsuccessfully, this difficult aspect of their work. Because the study was undertaken during the early years of the AIDS epidemic, I was able to provide comparative responses of death work with metastatic cancer patients and AIDS patients. Utilizing Merton's theory of anomie, I also examined the differences between doctors, nurses, and social workers in managing problem cases.

The purpose of an investigation of patient/professional interaction should reveal ways in which patient care can be enhanced. This study suggests the utility of this model as a teaching tool for enhancing the productive work of health professionals in their work with the dying.

Appendix 1

SUPPORTIVE CARE SERVICE

MORE THAN 500 TERMINALLY ILL PATIENTS RECEIVE CARE AT EVERY YEAR. THE CARE OF THESE PATIENTS IS DIFFICULT AND CHALLENGING. DURING THE PAST DECADE, DR. , HAS DRAMATIZED THE PROBLEMS AND LED THE SEARCH FOR SIGNIFICANT ANSWERS. IN THE PAST THREE YEARS, A GROUP OF NURSES, PHYSICIANS, SOCIAL WORKERS AND CHAPLAINS AT CORNELL-NEW YORK HOSPITAL HAVE EXAMINED THE PROBLEMS FACING OUR PATIENTS.

A STUDY OF 50 HOSPITAL PATIENTS AWAITING TERMINAL CARE PLACEMENT, CARRIED OUT BY IN 1978, AND ANOTHER GROUP OF 50 SIMILAR PATIENTS STUDIED IN 1981 BY SHOWED MAJOR DIFFICULTIES IN A NUMBER OF AREAS. INADEQUATE PAIN CONTROL REMAINS A GREAT PROBLEM. DEPRESSION PRESENTS FREQUENT DIFFICULTY. PATIENT, FAMILY OR STAFF DISSATISFACTION EMERGE REPEATEDLY.

THE SUPPORTIVE CARE SERVICE COMMITTEE OF THE MEDICAL BOARD HAS DEVELOPED AN APPROACH FOR DEALING WITH THESE PROBLEMS MORE EFFECTIVELY THROUGH THE USE OF A CONSULTATION TEAM. OUR GOALS ARE AS FOLLOWS:

1) RAPID, INFORMED CLINICAL EVALUATION OF THE TERMINALLY ILL PATIENT WITH EMPHASIS ON EFFECTIVE SYMPTOM CONTROL
2) CONCERN WITH THE PATIENT'S FAMILY AS WELL AS THE PATIENT;
3) PLANNING FOR FUTURE CARE AT HOME, IN A TERMINAL CARE FACILITY, OR IN THE HOSPITAL, AS APPROPRIATE; UP-TO-DATE INFORMATION ON AVAILABLE RESOURCES;
4) REDUCTION OF INAPPROPRIATE AND COSTLY PROCEDURES;
5) CONTINUITY OF CARE; AND
6) STUDY OF THE MANY PROBLEMS OF TERMINALLY ILL PATIENTS AND IMPROVED APPROACHES TO DEALING WITH THEM.

THE CONSULTATION TEAM WILL USE RESOURCES THAT ALREADY EXIST IN THIS MEDICAL CENTER AND OUR COMMUNITY. OUR AIM IS TO PROVIDE HELP IN CONTROLLING DISTRESSING SYMPTOMS AND TO CONCERN OURSELVES WITH ALL THE OTHER NEEDS OF THE DYING PATIENT AND HIS FAMILY. THERE IS EVIDENCE THAT IF SYMPTOMS ARE BETTER CONTROLLED AND MORE SUPPORT IS PROVIDED, MORE TIME MAY BE SPENT AT HOME. SOME PATIENTS WILL CHOOSE TO DIE AT HOME. FRAGMENTATION AND DISRUPTION OF CARE CAN BE REDUCED. "THE CONCEPT OF THE HOSPICE TEAM IS ATTRACTIVE TO DOCTORS WHO WISH TO CONTINUE TO CARE FOR THEIR OWN DYING PATIENTS" REPORTS THE SUPPORT TEAM OF ST. THOMAS HOSPITAL, LONDON (LANCET, MAY 30, 1981, P. 1201).

THE SUPPORTIVE CARE TEAM HAS NO BEDS OF ITS OWN AND DOES NOT ASSUME MANAGEMENT OF PATIENTS. IT WILL GIVE ADVICE AND FAMILY SUPPORT WHEN FORMALLY INVITED TO DO SO BY THE PATIENT'S DOCTOR. THE NURSE COORDINATOR WILL SEE THE REFERRED PATIENT PROMPTLY

AND TELL THE PATIENT THAT THE CONSULTATION TEAM HAS BEEN ASKED BY HIS PHYSICIAN TO HELP. THE PATIENT IS EVALUATED, DISCUSSED WITH THE STAFF, AND SUGGESTIONS ARE WRITTEN IN THE HOSPITAL CHART. THE TEAM THEN CONTINUES TO WORK ALONGSIDE THE PATIENT'S OWN DOCTOR AND NURSES, IDENTIFYING PROBLEMS AS THEY ARISE AND GIVING HELP WITHOUT DUPLICATION OF FACILITIES. MEDICATION ORDERS WILL GENERALLY BE WRITTEN BY THE HOUSE-STAFF WITH SUGGESTIONS BY THE SUPPORTIVE CARE TEAM.

THE TEAM WILL GENERALLY SEE PATIENTS DAILY DURING THE WEEK AND AT OTHER TIMES AS NECESSARY. THE TEAM WILL BE AVAILABLE FOR CONSULTATION AT ALL TIMES ___ ALL PATIENTS WILL BE REVIEWED BY THE ENTIRE SUPPORTIVE CARE SERVICE AT OUR WEEKLY CLINICAL CONFERENCE. CLINICAL PHARMACOLOGY, ONCOLOGY AND PSYCHIATRY ARE STRONGLY REPRESENTED IN THE SUPPORTIVE CARE SERVICE. THE SCIENTIFIC AND CLINICAL RESOURCES AVAILABLE IN OUR CENTER REPRESENT AN OPPORTUNITY FOR EXCELLENT PATIENT CARE, INNOVATIVE RESEARCH AND SOUND TEACHING.

UNDER THE SPONSORSHIP OF THE AMERICAN COLLEGE OF PHYSICIANS, WE HAVE PLANNED A THREE DAY COURSE COVERING THE CLINICAL PHARMACOLOGY OF SYMPTOM CONTROL IN THE ELDERLY AND TERMINALLY ILL PATIENTS. HAS AGREED TO JOIN OTHER EXPERTS IN THIS COURSE, SCHEDULED FOR MAY 12 TO MAY 14, 1982, WITH PROCEEDINGS TO APPEAR AS AN ISSUE OF MEDICAL CLINICS OF NORTH AMERICA. A DETAILED SCHEDULE OF LECTURES AND DISCUSSIONS WILL BE AVAILABLE LATER THIS YEAR.

OUR TEAM MEMBERS ARE:

NURSE COORDINATOR:
ASSOCIATE NURSE:
PHYSICIAN:

ATTENDING STAFF:

CLINICAL PHARMACOLOGY:
INTERNAL MEDICINE:

ONCOLOGY:

PSYCHIATRY
SURGERY:
SOCIAL WORK:

HOME CARE:
CHAPLAINCY:

H.R.E.

Appendix 2

December 18, 1984

Dear Dr.

Harriet Goodman is a doctoral candidate in Social Welfare at the City University of New York Graduate Center and Hunter College School of Social Work. She is presently employed in the Division of Clinical Pharmacology as a research aide for the Supportive Care Service. Mrs. Goodman is preparing to begin her dissertation project, which she hopes to carry out in the Medical Center with hospital personnel and patient records. Although we believe that Mrs. Goodman's research is exempt from requirements for institutional review, we want to present the study methods to you so that you can confirm this.

The project Mrs. Goodman is considering would include the following:

1. A chart review of patients followed concurrently by the Supportive Care Service and Social Work.

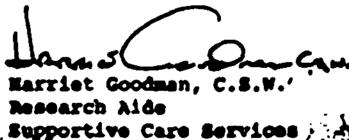
2. Focused interviews with nursing, medical and social work staff regarding ten patients who illustrate particular problems in the management of the terminally ill.

3. Observation of social work activity in Health Team Conference and Supportive Care Service rounds.

No data will be recorded in patient or employee identifiable form. The name of the institution will be disguised in any written material presented to the faculty. Participation in the study will be voluntary. The investigator will explain the project to all subjects and get oral consent for their participation.

Thank you for your consideration in this matter.

Sincerely yours,



Harriet Goodman, C.S.W.
Research Aide
Supportive Care Services

TO:

FROM: Harriet Goodman

RE: Doctoral Dissertation Research

DATE: May 23, 1985

Following our meeting of May 17, 1985, I am enclosing a description of my dissertation research and requesting the opportunity to interview a small group of medical staff nurses for the purposes of completing this doctoral project. My doctoral studies have been in Social Welfare. My project has been accepted by my Dissertation Committee at the Hunter College School of Social Work of the City University of New York. It has been approved by the Human Rights Committee of the Medical Center.

My project will be a dissertation in curriculum development. It will include a qualitative study of social work intervention with terminally ill metastatic cancer patients in hospital; a curriculum with detailed teaching materials; and plans for implementing and evaluating the curriculum as in-service training for hospital personnel.

Five concepts from medical sociology illustrating problems of managing dying patients in-hospital form the basis for a study of social work intervention with terminally ill metastatic cancer patients. I have developed a typology of these problems, operationally defining the concepts by constructing a series of indicators for each. I have developed materials for the study including forms for recording chart review and observational data, as well as focused interview schedules.

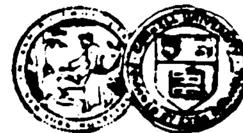
Methods for the proposed study consist of:

-- A retrospective chart review of 47 patients followed by Social Work and Supportive Care Service for more than one month between November 30, 1983 and December 1, 1984.

-- Observation of four sequential Health Team Conference rounds of ten social workers who have terminally ill metastatic cancer patients in their caseloads.

-- Prospective identification of terminally ill metastatic cancer patients illustrative of the problem types.

-- Triangulated interviews with social work, medical nursing, and medical personnel to develop case material on these selected cases.



I will require an N of ten to fifteen as a sample of patients illustrative of the problem types. Pre-testing of the attached format indicates that the interview will take approximately thirty minutes to administer. I therefore anticipate that the time required of nursing staff will be less than eight hours distributed over the medical service floors. Participation is obviously voluntary. It gives staff nurses an opportunity to discuss difficult management situations.

I hope that you will agree to let me interview your staff for the purposes of my study. I will of course be pleased to share my findings with your Department in any way you would find beneficial.

Appendix 3

Date: July 3, 1985

To: Medical and Surgical Social Work Staff

From: Harriet Goodman

Re: Summary of July 3 Meeting

Thank you for meeting with me today. I would like to summarize the discussion we had regarding your participation in my dissertation research. My study will include triangulated interviews of social work, nursing, and medical staff. The purpose of these interviews is to gather descriptive data about terminally ill metastatic cancer patients in hospital. These data will form the basis of a curriculum for hospital personnel to improve their skills in working with such patients.

The interviews will take approximately a half hour each. I will be tape recording the interviews. The study has been IRB approved, and the Department of Nursing has agreed to have its staff be interviewed. The content of the interviews will remain confidential. No data will be recorded in patient or employee identifiable form. The name of the institution, employees, and patients will be disguised in any written material.

I hope you will all be willing to be interviewed for the study. I also hope you will assist me in identifying appropriate cases which you may encounter in your practice. I am interested in locating patients who exemplify problems in five areas:

Toxic Patients or Family Members
Failure of the Acute Care System
to Meet Terminal Care Needs
Social Death and Disengagement Behaviors
Death Trajectory
Awareness Contexts

If you encounter a terminally ill patient with metastatic cancer who appears to be a management problem and you cannot relate him or her to a specific problem type, I would also want to consider the patient for my study.

If you want to suggest patients for the study, you may contact me at ex. May I remind you that , still taking referrals for cancer patients with pain, as in the past with the approval of the patient's attending physician. can be reached at

Thank you for your participation in the meeting today. I am looking forward to working with you over the next few months. You all have much to contribute to my work.

Date: August 14, 1985

To: Medical and Surgical Social Work Staff

From: Harriet Goodman

Thanks to the efforts of several social workers who have suggested patients for my study, I have collected interview data on four patients. These cases have yielded very interesting descriptive material, so that I feel my research has gotten off to a good start.

I hope you will continue to keep my work in mind and think about my study needs as you come upon problematic metastatic cancer patients. I encourage you to call me, even if you are uncertain as to the appropriateness of a particular patient.

Thank you for your continuing support of my doctoral studies.

Appendix 4

TRIANGULATED INTERVIEW CODE SHEET

Patient ID Code_____Age___Sex___Marital Status____Primary CA________Pt Hospital Days____________

Service________SW ID Code__________Interview Date___________Informant Title______________________

Assumed Problem Types____

INVENTORY OF PROBLEMS

Spontaneous Responses | Prompted Responses

Toxic patient behaviors

Toxic family behaviors

Low technological or educational interest

Disease unresponsive to curative therapies

Uncertain trajectory

Incongruent trajectory

Interferes with work routines

Interferes with sentimental order

Closed awareness context

Mutual pretext awareness

Open awareness

Disengagement behaviors by staff

Disengagement behaviors by family

Disengagement behaviors by patient

DATA COLLECTION FORM

Chart Review

Patient ID_______ Age____ Primary Diagnosis_____________ Worker ID____

Medical	Nursing	Social Work

Appendix 5

TRIANGULATED INTERVIEW FORMAT

Patient ID Code______Age____Sex_____ Marital Status_____

Primary CA___________Pt Hospital Days______Pt Service______________

SW ID Code___________Inteview Date____________

Informant Title____________Assumed Problem Types__________________

____

I'm Harriet Goooman. I work with Dr   as a research assistant for the Supportive Care Service. I'm also doing my doctoral dissertation research here on the care of terminally ill cancer patients. I would like to interview you for my study on treating dying patients in acute care hospitals. I'd like to spend an hour with you in total, but we could divide the time into shorter periods if that would be more convenient. As you can see, I have a tape recorder in my pocket. Would you mind if I left it on while we spoke? Your responses will of course be kept confidential.

1. How long have you been working on the unit?

2. Where were you working before that?

3. What do you see as the good/gratifying things about working on this unit?
   Probes: What is good about working here for you?
           Can you give me some examples of what you mean?

4. What do you see as the difficult/problematic/hard things for you about working on this unit?
   Probes: What is difficult about it for you?
           Can you give me some examples of what you mean?

5. I understand that Mr./Mrs.________might be an interesting subject for my study. Could we talk about him/her? How long have you worker with him/her? Would you say that s/he is a typical patient for this unit? What about him/her is typical (atypical)?
   Probes: What is unique about this patient?
           Tell me more about what you mean?
           Can you give me some examples?

6. I've heard that/I understand that... (examples from problem categories that are assumed to apply to patient)? Can you tell me something about this?

7. The experience with dying patients in hospitals has sometimes been that... (examples from problem categories that have not previously been mentioned in the interview)? Have you seen any of these things with this patient?

8. Can you tell me how you've handled some of these problems?

9. Has that helped?

10. Have you sought the help of your peers?

11. Has that helped?

12. Have you sought the help of other health workers?

13. Has that helped?

14. Have you sought the help of the patient's family?

15. Has that helped?

16. Have you (or doctors) tried to use medications to help with these problems?

17. Has that helped?

18. Has anyone suggested a psychiatric or social work referral?

19. How have those worked out.

20. What do you think has helped this situation the most?

21. Are there any other things you'd like to tell me that we haven't discussed? I will be around the floor interviewing other people for the next few days. If you think of anything you want to add, please stop me and let me know. Thank you for your time and for agreeing to participate in my study. You've really been helpful!

SELECTED BIBLIOGRAPHY

Albrecht, Gary L.; Vivian G. Walker; and Judith A. Levy. "Social Distance from the Stigmatized: A Test of Two Theories." Social Science and Medicine 16 (1982): 1319-1327.

Altman, Dennis. AIDS in the Mind of America. New York: Anchor-Press/Doubleday, 1986.

Altman, Lawrence K. "Studies of Young Doctors Find Anxiety About Caring for AIDS Patients." The New York Times, 9 June 1987, C14.

American College of Physicians, Health and Public Policy Committee. "Drug Therapy for Severe Chronic Pain in Terminal Illness." Annals of Internal Medicine 99 (September 1983): 870-873.

American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. Washington, D.C.: American Psychiatric Association, 1980.

Barnes, Deborah M. "Brain Damage by AIDS Under Active Study." Science 235 (27 March 1987): 1574-1577.

Batchelor, Walter F. "AIDS: A Public Health and Psychological Emergency." American Psychologist 39 (November 1984): 1279-1283.

Bayer, Ronald A.; Daniel Callahan; John Fletcher; Thomas Hodgson; Bruce Jennings; David Monsees; Steven Sieverts and Robert Veatch. "The Care of the Terminally Ill: Morality and Economics," The New England Journal of Medicine 309 (15 December 1983): 576-582.

Bennett, Joanne. "AIDS: What Precautions Do You Take in the Hospital." American Journal of Nursing (August 1986): 952-953.

Beszterczey, M. "Staff Stress on a Newly Developed Palliative Care Service: The Psychiatrist's Role." Canadian Psychiatric Association Journal 22 (November 1977): 347-353.

Blanchard, Christiana G.; John C. Ruckdeschel; Edward B. Blanchard; John G. Arena; Nancy L. Saunders; and E. Drew Malloy. "Interactions Between Oncologists and Patients During Rounds." Annals of Internal Medicine 99 (November 1983): 694-699.

Boffey, Philip M. "Doctors Who Shun AIDS Patients Are Assailed By Surgeon General." The New York Times, 10 September 1987, 1(A) and 11(B).

Bosk, Charles. "The Field Worker as Watcher and Witness." Hastings Center Report, 15 (June 1985): 10-14.

Bruyn, Severyn T. "The New Empiricists: The Participant Observer and Phenomenologist. In Qualitative Methodology: Firsthand Involvement in the Social World, ed. William J. Filstead, Chicago: Markham Publishing Company, 1970.

Carey, Raymond G. and Emil J. Posavac. "Attitudes of Physicians on Disclosing Information to and Maintaining Life for Terminally Ill Patients." Omega 9 (1978-79): 67-76.

Cartwright, Ann. Human Relations and Hospital Care. London: Routledge and Kegan Paul, 1964.

Casselith, Barrie R.; Edward J. Lusk; David S. Miller; Lorraine L. Brown; and Clifford Miller. "Psychosocial Correlates of Survival in Advanced Malignant Disease." The New England Journal of Medicine 312 (13 June 1985): 1551-1555.

_______________ and Judy A. Donovan. "Hospice: History and Implications of the New Legislation." Journal of Psychosocial Oncology 1 (Spring 1983): 59-69.

Centers for Disease Control. "Update: Human Immunodeficiency Virus Infections in Health-Care Workers Exposed to Blood of Infected Patients. Morbidity and Mortality Weekly Report 36 (22 May 1987): 285-289.

_______________. "Guidelines for Prevention of Transmission of Hıman Immunodeficiency Virus and Hepatitis B to Health-Care and Public Safety Workers." Morbidity and Mortality Weekly Report 38 (23 June 1989): 3-37.

Chiriboga, David A.; Gary Jenkins; and June Bailey. "Stress and Coping Among Hospice Nurses: Test of an Analytic Model." Nursing Research. 32 (September-October 1983): 294-299.

Coser, Rose Laub. "Some Social Functions of Laughter." Human Relations 12 (May 1959): 171-182.

Cottrell, Leonard S. and Eleanor R. Sheldon. "Problems of Collaboration between Social Scientists and Practicing Physicians." The Annals of the American Academy of Political and Social Science 346 (March 1953): 127-131.

Crary, William G. and Gerald C. Crary. "Staff Responses to Fatally Ill Patients." In Interacting with Dying Patients, ed. Geraldine V. Padilla, Veronica Baker, and Vikki A. Dolan, Durante, California: City of Hope Medical Center, 1975.

Critical Care Committee of the Massachusetts General Hospital "Optimum Care for Hopelessly Ill Patients." The New England Journal of Medicine 295 (April 12, 1976): 362.

Dickerson, George A. and Algene A. Pearson. "Differences in Attitude Toward Terminal Patients Among Selected Medical Specialties of Physicians." Medical Care 17 (June 1979): 682-685.

Dolenc, Danielle A. and Charles J. Dougherty. "DRGs: The Counter-revolution in Financing Health Care." Hastings Center Report 15 (June 1985): 19-29.

Dostoyesky, Fyodor. The Brothers Karamazov. Translated by David Magarshavic. New York: Penguin Books, 1958.

Douglas, Carolyn; Concetta M. Kalman; and Thomas P. Kalman. "Homophobia Among Physicians and Nurses: An Empirical Study." Hospital and Community Psychiatry 36 (December 1985): 1309-1311.

Drossman, Douglas A. "The Problem Patient: Evaluation and Care of Medical Patients with Psychosocial Disturbances." Annals of Internal Medicine 88 (March 1978): 367-69.

Epstein, Irwin. "Quantitative and Qualitative Research Methods: Conflict or Continuum." In Research in Social Work, 2nd Ed., ed. Robert Grinnell, Jr., Itasca, Illinois: Peacock Press, 1985.

Erle, Henry. "Terminal Care: The National Scene and the Individual Patient." The Medical Clinics of North America 66 (September 1982): 1161-1168.

Feifel, Herman, ed. The Meaning of Death. New York: McGraw-Hill 1959.

Feingold, Sydney M. "Protecting Health Personnel." In The AIDS Epidemic, ed. Kevin M. Cahill, New York: St. Martin's Press, 1983.

Forstein, Marshall. "The Psychological Impact of AIDS." Seminars in Oncology 11 (March 1984): 77-82.

Fox, Daniel M. "AIDS and American Health Policy: The History and Prospects of a Crisis of Authority." The Milbank Memorial Fund Quarterly 64, Suppl. 1 (1986): 7-33.

Fox, Renee C. "Reflections and Opportunities in the Sociology of Medicine." Journal of Health and Social Behavior 26 (March 1985): 6-14.

Freidson, Eliot. The Profession of Medicine. New York: Dodd Mead and Company, 1970.

____________. "Prepaid Group Practice and the New 'Demanding Patient.'" Milbank Memorial Fund Quarterly (Fall 1973): 472-488.

____________. "The Reorganization of the Medical Profession." Medical Care Review 42 (Spring 1985): 11-35.

Fried, Charles. "Terminating Life Support: Out of the Closet!" New England Journal of Medicine 195 (12 April 1976): 390-391.

Glaser, Barney G. and Anselm L. Strauss. Time for Dying. Chicago: Aldine Publishing Company, 1968.

____________. The Discovery of Grounded Theory: Strategies for Qualitative Research. Chicago: Aldine Publishing Company, 1967.

Goffman, Erving. Asylums. Garden City, New York: Anchor Books, 1961.

Gray-Toft, Pamela A. and James G. Anderson. "Organizational Stress in the Hospital: Development of a Model for Diagnosis and Prediction." Health Services Research 19 (February 1985): 753-774.

Greer, David S. and Vincent Mor. Final Report of the National Hospice Study. Providence, Rhode Island: Brown University Program in Medicine and Center for Health Care Research, 1984.

Groves, James E. "Taking Care of the Hateful Patient." The New England Journal of Medicine 198 (20 April 1978): 885-887.

Hay, Donald and Donald Oken. "The Psychological Stresses in the Intensive Care Unit Nursing." Psychosomatic Medicine 34 (March/April 1972): 109-118.

Heagarty, Margaret C. "AIDS: A View from the Trenches." Issues in Science and Technology (Winter, 1987): 111-117.

Hoggatt, Loretta and Bernard Spilka. "The Nurse and the Terminally Ill Patient: Some Perspectives and Projected Actions." Omega 9 (1978-79): 255-266.

Holland, Jimmie C. and Susan Tross. "The Psychosocial and Neuropsychiatric Sequelae of the Acquired Immunodeficiency Syndrome and Related Disorders." Annals of Internal Medicine 103 (November 1985): a760-764.

Hospitals. "Educating Staff About AIDS Eases Hysteria." 1 (February 1984): 40-41.

Jeffrey, Roger. "Normal Rubbish: Deviant Patients in Casualty Departments." Sociology of Health and Illness 1 (1979): 92-98.

Kalish, Richard A. "Social Distance and the Dying." Community Mental Health Journal 2 (Summer 1966): 152-155.

Kasper, A.M. "The Doctor and Death." In The Meaning of Death, ed. Herman Fiefel, New York: McGraw Hill, 1959.

Kastenbaum, Robert. Death, Society, and Human Experience. St. Louis: The C.V. Mosby Company, 1981.

____________ and Ruth Aisenberg. The Psychology of Death. New York: Springer Publishing Company, 1972.

Kayal, Philip M. "Morals, Medicine, and the AIDS Epidemic." Journal of Religion and Health, 24 (Fall 1985): 218-238.

Kelly, Jeffrey; Janet S. St. Lawrence; Steve Smith, Jr.; Harold V. Hood; and Donna J. Cook. "Stigmatization of AIDS Patients by Physicians." American Journal of Public Health 77 (July 1987): 789-791.

Krim, Mathilde. "A Chance at Life for AIDS Sufferers." The New York Times, 8 August 1986, 32.

Kubler-Ross, Elizabeth. On Death and Dying. New York: Macmillan, 1969.

Laurence, Martha Keniston. "Dealing with the Difficult Older Patient." Canadian Medical Association Journal 134 (15 May 1986): 1122-1126.

Levinson. Peritz. "Obstacles in the Treatment of Dying Patients." American Journal of Psychiatry 132 (January 1975): 28-32.

Liederman, Deborah B. and Jean-Anne Grisso. "The Gomer Phenomenon." Journal of Health and Social Behavior 26 (September 1985): 224-227.

Lipsett. Don R. "Medical and Psychological Characteristics of 'Crocks.'" Psychiatry in Medicine 1 (1970): 15-17.

Livingston, Peter B. and Carl N. Zimet. "Death Anxiety: Anti-authoritarianism and Choice of Specialty in Medical Students." Journal of Nervous Mental Disease 140 (March 1965): 222-230.

Loewy, Eric H. "Duties, Fears and Physicians." Social Science and Medicine 22 (December 1986): 1363-1366.

Lorber, Judith. "Good Patients and Problem Patients: Conformity and Deviance in a General Hospital." Journal of Health and Social Behavior 16 (June 1975): 216-218.

Lukashok, Herbert. "Hospice Care Under Medicare: An Early Look." Paper presented at the International Conference on Health Policy, Jerusalem, Israel, 1987.

Masterson-Allen, Susan; Vincent Mor; Linda L. Laliberte; and L. Montiero. "Staff Burnout in a Hospice Setting." Hospice Journal.

Mauksch, Hans O. "The Organizational Context of Dying." In Death: The Final Stage of Growth, ed. Elizabeth Kubler-Ross, Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1975.

McKusick, Leon; William Horstman; Donald Abrams; and Thomas J. Coates. "The Psychological Impact of AIDS on Primary Care Physicians." Western Journal of Medicine 14 (June, 1986): 751-752.

Mechanic, David. "Cost Containment and the Quality of Medical Care." Milbank Memorial Fund Quarterly 63 (Summer 1985): 453-475.

Merton, Robert K. Social Theory and Social Structure. New York: The Free Press, 1968.

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

Mor, Vincent and Laliberte, Linda. "Burnout Among Hospice Staff." Health and Social Work 9 (Fall. 1984), 274-283.

Mount, B.M.; I. Ahemian; and J.F. Scott. "Use of the Brompton Mixture in Treating the Chronic Pain of Malignant Disease." Canadian Medical Association Journal 115 (17 July 1976): 122-24.

Nelson, William J.; Linda Maxey; and Steven Keith. "Are We Abandoning the AIDS Patient." RN (July 1984): 18-19.

Nichols, Stuart E. "The Social Climate When the Acquired Immune Deficiency Syndrome Developed." In Psychiatric Implications of AIDS, ed. Stuart E. Nichols and David G. Ostrow, Washington, D.C.: American Psychiatric Press, Inc., 1984.

Novack, Dennis H.; Robin Plumer; Raymond L. Smith; Herbert Ochitill; Gary R. Morrow; and John M. Bennett. "Changes in Physicians' Attitudes Toward Telling the Cancer Patient." Journal of the American Medical Association 241 (2 March 1979): 897-900.

Noyes, Russell Jr. and John Clancey. "The Dying Role: Its Relevance to Improved Patient Care." In Hospice Care: Principles and Practice, ed. Charles A. Corr and Donna Corr, New York: Springer Publishing Company, 1983.

O'Donnell, Lydia and Carl R. O'Donnell. "Hospital Workers and AIDS: Effect of In-Service Education on Knowledge and Perceived Risks and Stresses." New York State Journal of Medicine 87 (May 1987): 278-280.

Ostrow, David G. "Medical Responses to Acquired Immune Deficiency. In Psychiatric Implications of AIDS, ed. Stuart E. Nichols and David G. Ostrow, Washington, D.C.: American Psychiatric Press, Inc., 1984.

Parsons, Talcott, The Social System. New York: The Free Press, 1951.

Pearlman, B.A.; A. Stotsky; and J.R. Dominick. "Attitudes Towards Death Among Nursing Home Personnel." Journal of Geriatric Psychology. 114 (1969): 693-700.

Pearshall, Marion. "Participant Observation as Role and Method in Behavioral Research." Nursing Research 28 (May 1965): 119-132.

Plumeri, Peter A. "The Refusal to Treat: Abandonment and AIDS." Journal of Clinical Gastroenterology 6 (June 1984): 281-284.

Price, Trevor R. and Bernard J. Bergen. "The Relationship to Death as a Source of Stress for Nurses in a Coronary Care Unit." Omega 8 (1977): 229-238.

Quint, Jeanne C. "Awareness of Death and the Nurse's Composure." Nursing Research 15 (Winter 1966): 49-55.

____________. "The Uses if Uncertainty." In Medical Men and Their Work, ed. Eliot Freidson and Judith Lorber. Chicago: Aldine-Atherton, 1972.

Rabkin, Mitchell; Gerald Gillerman; and Nancy R. Rice. "Orders Not to Resuscitate." The New England Journal of Medicine 295 (April 12, 1976): 364-366.

Rea, M. Priscilla; Shirley Greenspoon; and Bernard Spilka. "Physicians and the Terminal Patient." Omega 6 (1975): 291-302.

Reis, Richard K.; John A. Bokan; Wayne J. Katon; and Arthur Kleinman. "The Medical Care Abuser: Differential Diagnosis and Management." The Journal of Family Practice 13 (August 1981): 257-265.

Richardson, Jean L.; Thomas Lochner; Kimberly McGuigan; and Alexandra M. Levine. "Physicians Attitudes and Experience Regarding the Care of Patients with Acquired Immunodeficiency Syndrome (AIDS) and Related Disorders (ARC)." Medical Care 25 (August 1987): 675-685.

Saunders, Cicely. "The Moment of Truth: Care of the Dying In Death and Dying, ed. L. Pearson, Cleveland, Ohio: Case University Press, 1960.

Schmeck, Harold M. "Grim New Ravage of AIDS: Brain Damage." The New York Times, 15 October 1985, C1-2.

Shem, Samuel. The House of God. New York: Dell, 1978.

Spradley, James P. Participant Observation. New York: Holt, Rinehart and Winston, 1980.

Stark, Doretta E. and Edith M. Johnson. "Implications of Hospice Concepts for Social Work Patients and Their Families in an Acute Care Teaching Hospital." Social Work in Health Care 9 (Fall 1983): 63-70.

Strain, James J. "The Anatomy of the Teaching Hospital." In Psychological Care of the Medically Ill, ed. James J. Strain and Stanely Grossman. New York: Appleton-Century Crofts, 1975.

Strauss, Anselm L. and Barney G. Glaser. Awareness of Dying. Chicago: Aldine Publishing Company, 1965.

___________; Shizuko Faagerhaugh; Barbara Suczek; and Carolyn Wiener. Social Organization of Medical Work. Chicago: University of Chicago Press, 1985.

Sudnow, David. Passing On: The Social Organization of Death. Englewood Cliffs New Jersey: Prentice-Hall, Inc., 1967.

___________. "Dying in a Public Hospital." In The Dying Patient, ed. Orville G. Brim, Jr., New York: Russell Sage Foundation, 1970.

Szasz, Thomas. "Malingering: 'Diagnosis' or Social Condition." AMA Archives of Neurology and Psychiatry 76 (1956): 432-33.

Travis, Terry A.; Russell Noyes, Jr.; and Dennis R. Brightwell. "The Care of Terminal Patients: A Statewide Survey." International Journal of Psychiatry in Medicine 5 (Summer 1974): 17-26.

Tycross, Robert G. and Sarah Fairfield. "Pain in Far Advanced Cancer." Pain 14 (1982): 303-310.

Vachon, Mary L.S. "Staff Stress in Hospice Care: A Theoretical Model." Manuscript 1983.

___________; W. Alan L. Lyall; and S.J.J. Freeman. "Measurement and Management of Stress in Health Professionals Working With Advanced Cancer Patients." Death Education 1 (1978): 365-375.

Valenti, William M. and Joseph P. Annarella. "Survey of Hospital Personnel in the Understanding of AIDS. American Journal of Infection Control 2 (14 April 1986): 60-63.

Veatch, Robert M. and Ernest Tai. "Talking About Death: Patterns of Lay and Professional Change." Annals of the American Academy of Political and Social Sciences 447 (January, 1980): 29-45.

Vladek, Bruce C. "Medicare Hospital Payment by Diagnostic Related Groups." Annals of Internal Medicine 100 (April 1984): 576-582.

Volberding, Paul and Donald Abrams. "Clinical Care and Research in AIDS." Hastings Center Report 15 (August 1985): 16-18.

Wachter, Robert M. "The Impact of the Acquired Immunodeficiency Syndrome on Medical Residency Training." New England Journal of Medicine 314 (January 16, 1986): 177-179.

Weisman, Avery D. On Dying and Denying: A Psychiatric Study of Terminality. New York: Behavioral Publications, Inc., 1972.

Weiss, K. "AIDS Turmoil in the Medical Profession." The New Physician 32 (January 1983): 14-16.

Wertz, Dorothy C.; James R. Sorensonn; Linette Liebling; Lawrence Kessler; and Timothy C. Heeren. "Knowledge and Attitudes of AIDS Health Care Providers Before and After Education Programs." Public Health Report 102 (May-June 1987): 248-254.

Yancik, Rosemary. "Sources of Stress for Hospice Staff." Journal of Psychological Oncology 2 (Spring 1984): 21-31.

Youngner, Stuart J. "Do-Not-Resuscitate Orders: No Longer Secret, But Still a Problem." Hastings Center Report 18 (February 1987): 24-33.