

# AWARENESS OF DYING

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BY

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AND

Anselm L. Strauss



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# Preface

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*Once upon a time a patient died and went to heaven, but was not certain where he was. Puzzled, he asked a nurse who was standing nearby: "Nurse, am I dead?" The answer she gave him was: "Have you asked your doctor?"*

—ANONYMOUS,      circa 1964

Recently *The New York Times* reported: "VERY ILL CHILDREN TOLD OF DISEASE; Leukemia Patients at N.I.H. Not Shielded From Truth. . . . A child should always be told the truth, even when he has an incurable disease such as leukemia, according to two researchers who interviewed 51 children hospitalized at the National Cancer Institute, Bethesda, Maryland, for treatment of leukemia." This kind of news item reflects the growing concern among researchers and public about matters which touch on morality as much as on the technical aspects of medicine. The rapidly increasing proportion of elderly people in the American population presents a range of personal and social questions; not the least is how they view their newly won longevity (often including anticipated years of chronic disease) as well as their attitudes toward death. In consequence, many geriatric specialists are beginning to study American attitudes toward death, while others, spurred on by what seems a senseless prolonging of life within hospital walls by medical technology run wild, are raising questions about death and dying in American life.

Our book is no exception to this trend; indeed, we would further it. We wish to contribute toward making the management of dying—by patients, families and health professionals—

more rational and compassionate (and the two are far from incompatible). The chief differences between our approach and others' can be quickly summarized. Recognizing that most Americans are now dying inside hospitals, we have focused upon what happens when people die there. We have focused on the interaction between hospital staffs and patients, rather than on the patients themselves. We have reported on contexts of action rather than merely on "attitudes toward death." And we have been less concerned with death itself than the process of dying—a process often of considerable duration.

This approach reflects our sociological perspective, for we have attempted to channel our reforming impulses into an inquiry not at all medical in character. If increasingly Americans are dying within medical establishments, surrounded more by nurses and physicians than by kinsmen, then how do these representatives of the wider society manage themselves and their patients while the latter are dying? How is the hospital's organization capitalized upon in this process? What forms of social action, transitory or more permanent, arise while handling the dying of people? What are the social consequences for the hospital and its staff, as well as for the patients and their families?

To answer these kinds of questions, we did intensive field-work (involving a combination of observation and interviewing) at six hospitals located in the Bay area of San Francisco. We chose a number of medical services at each hospital, selected, as we shall explain later, to give us maximum exposure to different aspects of dying—locales where death was sometimes speedy, sometimes slow; sometimes expected, sometimes unexpected! sometimes unanticipated by the patient, sometimes anticipated; and so on. The reader who is unacquainted with this style of field research need only imagine the sociologist moving rather freely within each medical service, having announced his intention of "studying terminal patients and what happens around them" to the personnel. The sociologist trails personnel around the service, watching them at work, sometimes questioning them about its details. He sits at the nursing station. He

listens to conversations himself. Occasionally he queries the staff members, either about events he has seen or events someone has told him about. Sometimes he interviews personnel at considerable length, announcing "an interview," perhaps even using a tape recorder. He sits in on staff meetings. He follows, day by day, the progress of certain patients, observing staff interaction with those patients and conversation about the patients among the personnel. He talks with patients, telling them only that he is "studying the hospital." His fieldwork takes place during day, evening and night, and may last from ten minutes to many hours.

In presenting what we observed by such methods, we might have organized our analysis in this book to highlight differences and similarities among the various medical services. Instead, we chose to offer our readers a more abstract—and so more powerful—explanatory theoretical scheme. This scheme arose from scrutiny of the data and should illuminate the data far more than a comparative analysis of the medical services. Our analysis is based upon what we term "awareness context," which is discussed in Chapter I; here we need only note that this term refers to who, in the dying situation, knows what about the probabilities of death for the dying patient. It makes a great deal of difference who knows what, and the use of this scheme allows the organization of many events that otherwise might seem disconnected or paradoxical.

The efficiency of the scheme allows us to claim—we believe with some persuasiveness—that discernible patterns of interaction occur predictably, or at least non-fortuitously, during the process of hospitalized dying, and that explicit knowledge of these patterns would help the medical staff in its care of dying patients. Physicians and nurses tend to regard such events either in mythological terms (some mythologies are touched upon later) or to discount patterned events in favor of the uniqueness of events (everyone is "a different personality," so dies differently and must be handled differently). A group of eminent physicians hearing of our analysis before its actual publication,

we were told, remarked flatly that sociologists have nothing useful to offer physicians. Theirs was a natural reaction to the invasion by outsiders of a delicate and somewhat mysterious realm. We have not meant to scientize this realm, nor to offer commentary that would freeze and prematurely professionalize care for the dying by hospital staffs. Our intent was, above all, to ask whether people can die socially before they die biologically, and what this means for human relationships. If our report makes matters easier for people who must live around the dying (and vice versa), it will only be because critical intelligence is brought to bear on our findings and on common practices in American hospitals. Perhaps, then, hospital personnel will not laugh quite so wryly at the anonymous lines, quoted above, about the patient's puzzled query of a nurse.

*Awareness of Dying* was planned as the first of a series of four monographs resulting from a six-year research financed by the National Institutes of Health (grant number NU 00047). The second monograph will discuss the course, or trajectory, of dying; and the third, by Jeanne Quint, will be titled *The Nurse Student and the Dying Patient*. A fourth volume will deal with staff-family interaction in dying situations.

The authors of *Awareness of Dying* are indebted to a great many people. They wish especially to thank the third member of the project team, Miss Jeanne Quint, for her almost daily invaluable support; also Mrs. Elaine MacDonald and Miss Ruth Fleshman, who assisted in data collection during an early phase of the project. Howard Becker, editor of the "Observations" series in which this book appears, read our original manuscript with an appreciative but unusually critical eye, and we wish to thank him here. From a number of colleagues, we received general support and specific commentary: among them, Herbert Blumer, Fred Davis, and Louis Schaw. Strauss appreciates his conversations with Leonard Schatzman. We had a very useful early exchange with Dr. Melvin Sabshin and equally useful later conversations with several nurse educators, especially Miss Helen Nahm, Miss Jeanne Hallburg and Mrs. Mildred McIntyre.

Like all field researchers, we are especially indebted to many persons who worked at the field-work locales. They are far too many to cite by name, but we wish at least to express our gratitude to them and their institutions: especially Moffitt Hospital (University of California Medical Center, San Francisco); Providence Hospital, Oakland; the Veterans Administration Hospital at Oakland; the Napa State Mental Hospital; the San Francisco General Hospital; and Highland Hospital in Oakland.

Miss Karen Many edited and Mrs. Kathleen Williams helped to type first draft manuscript. Miss Bess Sonoda, our project secretary, is the hitherto "without whom" unsung heroine of our manuscript; we thank her, too.

*Barney G. Glaser and Anselm L. Strauss*  
*San Francisco*

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# Part One

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## Introduction



# The Problem of Awareness of Dying

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American perspectives on death seem strangely paradoxical. Our newspapers confront the brutal fact of death directly, from the front page headlines to the back page funeral announcements. Americans *seem* capable of accepting death as an everyday affair—someone is always dying somewhere, frequently under most unhappy circumstances. To account for this absorbing interest in death (even death by violence), one need not attribute to the reading public an especially vigorous appetite for gruesome details. Death is, after all, one of the characteristic features of human existence, and the people of any society must find the means to deal with this recurring crisis. Presumably one way to deal with it is to talk and read about it.

Curiously, however, Americans generally seem to prefer to talk about particular deaths rather than about death in the abstract. Death as such has been described as a taboo topic for us, and we engage in very little abstract or philosophical discussion of death.<sup>1</sup> Public discussion is generally limited to the social consequences of capital punishment or euthanasia.

Americans are characteristically unwilling to talk openly about the *process* of dying itself; and they are prone to avoid telling a dying person that he is dying. This is, in part, a moral attitude: life is preferable to whatever may follow it, and one should not look forward to death unless he is in great pain.

This moral attitude appears to be shared by the professional people who work with or near the patients who die in our

<sup>1</sup> Herman Feifel, "Death," in Norman L. Farberow, *Taboo Topics* (New York: Atherton Press, 1963), pp. 8-21.

hospitals. Although trained to give specialized medical or nursing care to terminal patients, much of their behavior towards death resembles the layman's. The training that physicians and nurses receive in schools of medicine or nursing equips them principally for the technical aspects of dealing with patients. Medical students learn not to kill patients through error, and to save patients' lives through diagnosis and treatment, but their teachers emphasize very little, or not at all, how to talk with dying patients, how—or whether—to disclose an impending death, or even how to approach the subject with the wives, children and parents of dying patients.<sup>2</sup>

Similarly, students at schools of nursing are taught how to give nursing care to terminal patients, as well as how to give "post-mortem care," but only recently have the "psychological aspects" of nursing care been included in their training. Few teachers talk about such matters, and they generally confine themselves to a lecture or two near the end of the course, sometimes calling in a psychiatrist to give a kind of "expert testimony."<sup>3</sup> Although doctors and nurses in training do have some experience with dying patients, the emphasis is on the necessary techniques of medicine or nursing, not on the fact of dying itself. As a result, sometimes they do not even know they are treating or caring for a dying patient.

Although physicians and nurses may thus exhibit considerable technical skill in handling the bodies of terminal patients, their behavior to them otherwise is actually outside the province of professional standards. In hospitals, as in medical and nursing schools, discussion of the proper ways to manage dying patients tends to be only in strictly technical medical and nursing terms. Also, staff members are not required to report to

<sup>2</sup> These statements are the result of a secondary analysis of field-notes from a study of the University of Kansas Medical School; see Howard S. Becker, Blanche Geer, Everett C. Hughes, and Anselm L. Strauss, *Boys in White* (Chicago: University of Chicago Press, 1961).

<sup>3</sup> Jeanne C. Quint and Anselm L. Strauss, "Nursing Students, Assignments, and Dying Patients." *Nursing Outlook*, Vol. 12 (January 1964); also Jeanne C. Quint, *The Nurse Student and the Dying Patient* (New York: The Macmillan Company, in press, 1966).

each other, or to their superiors, what they have talked about with dying patients. As we will discuss later, they are "accountable" only for the technical aspects of their work with the dying.<sup>4</sup>

Medical and nursing personnel commonly recognize that working with and around dying patients is upsetting and sometimes traumatic. Consequently some physicians purposely specialize in branches of medicine that will minimize their chances of encountering dying patients; many nurses frankly admit a preference for wards or fields of nursing where there is little confrontation with death. Those who bear the brunt of caring for terminal patients tend to regard its hazards as inevitable—either one "can take" working with these patients or he cannot. Physicians and nurses understandably develop both standardized and idiosyncratic modes of coping with the worst hazards. The most standard mode—recognized by physicians and nurses themselves—is a tendency to avoid contact with those patients who, as yet unaware of impending death, are inclined to question staff members, with those who have not "accepted" their approaching deaths, and with those whose terminality is accompanied by great pain. As our book will attest, staff members' efforts to cope with terminality often have undesirable effects on both the social and psychological aspects of patient care and their own comfort. Personnel in contact with terminal patients are always somewhat disturbed by their own ineptness in handling the dying.

The social and psychological problems involved in terminality are perhaps most acute when the dying person knows that he is dying. For this reason, among others, American physicians are quite reluctant to disclose impending death to their patients,<sup>5</sup> and nurses are expected not to disclose it without the consent of the responsible physicians. Yet there is a prevailing belief among them that a patient who really wants to know will

<sup>4</sup> Anselm L. Strauss, Barney G. Glaser, and Jeanne C. Quint, "The Nonaccountability of Terminal Care," *Hospitals*, 38 (January 16, 1964), pp. 73-87.

<sup>5</sup> Feifel, *op. cit.*, p. 17.

somehow discover the truth without being told explicitly. Some physicians, too, maneuver conversations with patients so that disclosure is made indirectly. In any event, the demeanor and actions of a patient who knows or suspects that he is dying differ from those of a patient who is not aware of his terminality. The problem of "awareness" is crucial to what happens both to the dying patient and to the people who give him medical and nursing care.

From one point of view the problem of awareness is a technical one: should the patient be told he is dying—and what is to be done if he knows, does not know, or only suspects? But the problem is also a moral one, involving professional ethics, social issues, and personal values. Is it really proper, some people have asked, to deny a dying person the opportunity to make his peace with his conscience and with his God, to settle his affairs and provide for the future of his family, and to control his style of dying, much as he controlled his style of living? Does anyone, the physician included, have the right to withhold such information? Someone must decide whether to disclose, and when to disclose, but on whose shoulders should this responsibility fall—the physician, the family, or the patient? The rationale for making such decisions, as well as for designating who will make them, is not based on technical reasoning alone but also on various ethical, moral and human considerations.

Both the human and the technical aspects of the awareness problem are becoming increasingly momentous, for at least two reasons. One is that most Americans no longer die at home. Last year in the United States, 53 per cent of all deaths occurred in hospitals, and many more in nursing homes.<sup>6</sup> The family may be present much of the time while a person is dying, but he is also surrounded by many strangers, however compassionate and technically skilled they may be. Dying away from home is compounded by a noticeable and important medical

<sup>6</sup> Robert Fulton, "Death and Self," *Journal of Religion and Health*, 3 (July 1964), p. 364.

trend: because medical technology has vastly improved, fewer people are dying from acute diseases and more from chronic diseases. Moreover, the usual duration of most chronic diseases has increased, so that terminal patients, in the aggregate, take longer to die than they used to. They may spend this time in the hospital, or return several times to the hospital while they are dying.

Dying away from home, and from a chronic disease, will become more common during the next decades, making the problem of "awareness" even more salient to everyone concerned. Hospitals are scientific establishments and staff members are expected to make competent judgments about what is wrong with patients and to assess their prospects for recovering—or not recovering. For this very reason more and more terminal patients will persist in asking questions, and in expecting explicit, detailed answers, about the nature of their illness, how long the hospitalization will last, and why, and in what shape they will leave for home. Inevitably, more of them will discover, or be told, the truth. (The widespread improvement in educational level will strengthen these trends.) And so it is predictable that the problem of awareness will become more and more central to what happens as people pass from life to death in American hospitals. That problem is the principal subject of our book.

## AWARENESS AND THE STUDY OF INTERACTION

This book will be directed to two audiences: those who are concerned with dying in our hospitals (especially those who must deal with it), and sociologists (especially those who study social interaction). Our book, then, can be read for its practical details as well as for its theoretical aspects. Writing to such a double audience is only slightly hazardous, we believe, because we are convinced that sociologists cannot say anything profoundly useful unless it is of theoretical interest to sociologists themselves.

As noted, our book is based upon extensive field observation and interviewing done at hospitals in the San Francisco metropolitan area. The research was part of a larger study of how nursing and medical personnel give care to terminal patients. In Appendix A, both the larger project and the field-work methods which underlie our conclusions in this book are described briefly. In general, our project was focused on what kinds of thing happen around patients as they lie dying in American hospitals. In this book, we began by narrowing that focus to the following questions. What are the recurrent kinds of *interaction* between dying patient and hospital personnel? What kinds of *tactics* are used by the personnel who deal with the patient? Under what conditions of hospital organization do these kinds of interaction and these tactics occur, and how do they affect the patient, his family, the staff, and the hospital itself, all of whom are involved in the situations surrounding dying? In finding answers to these questions, we discovered that most variations could be accounted for by what each party to the dying situation was aware of about the patient's fate. Thus we further narrowed our focus to dealing with these questions as they related to awareness: a powerful explanatory variable.

These questions are of immense practical relevance to hospital personnel, who are confronted daily with the exceedingly delicate and difficult task of caring for terminal patients. But outsiders like ourselves, however observant, can contribute little by merely narrating the difficulties experienced by hospital "insiders," and even less by offering a few suggestions for coping better with those difficulties. (We are chary of prescriptions and evaluations, though in Chapter 14 we shall address ourselves to how our theory of awareness bears upon issues of practical understanding and control.) A sociologist contributes most when he reports what he has observed in such a fashion that his account rings true to insiders, but also in such a fashion that they themselves would not have written it. That