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## PREFACE

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 fieldwork (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 nonfortuitously, 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.

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San Francisco