

# Preface

Albert R. Jonsen—a gentle, compassionate, superbly educated former priest and perhaps the first clinical ethics consultant ever—had just helped two young parents and the neonatology staff at Moffitt Hospital reach a painful decision. He had guided them to the sad, inescapable conclusion that life support could not keep the parents' premature, multiply handicapped newborn alive. The baby was inexorably dying. The parents and the staff reluctantly decided to stop life support and allow the baby to die.

I was a fully trained internist and brand-new bioethics fellow of Professor Jonsen's at the time. I had heard about the baby's predicament and observed from afar Professor Jonsen's ethics consultation about it. I naturally believed (as any clinically focused doctor would) that his consultative responsibilities in the case had ended with the decision to stop all but comfort care.

I happened to notice Professor Jonsen in his office the day after the formal consultation. He appeared weary and subdued. I asked whether he felt ill. He said, No, he had just returned from visiting this baby's parents again. Naively surprised, I asked why. He replied that, although he had served as the ethics consultant, not the hospital chaplain in the case, he had sensed something of a therapeutic relationship between himself and the parents. He, therefore, had felt a pastoral duty to see them through the ordeal of the baby's death.

His reply challenged me to step out of the narrow, strictly rational perspectives of both scientific medicine and academic ethics. Over the subsequent months of my bioethics fellowship, I began to see the importance of health professionals' recognizing and somehow addressing the spiritual dimension of illness. Later experiences as a missionary doctor in Africa and as a clinical ethics consultant in my own right back in the USA confirmed that impression and extended it to the psychological, social, and cultural dimensions of illness, too. I came to believe that *every* illness has multiple important dimensions, not just the bioscientific, and they all deserve attention.

Healthcare professionals who care for dying patients have an especially important responsibility to see the nonbioscientific dimensions of terminal illness addressed. That idea, of course, is not new. The modern hospice movement has

successfully drawn attention to them, and that attention now reaches into mainstream medical settings. But I wonder whether the progress has stalled. Other authors do, too, suggesting that the bioscientific has already co-opted the psychological, social, and spiritual [1] as palliative care practice conforms increasingly to the standards of an established medical specialty [2] and as scientific evidence begins to drive all clinical practice even at the end of life.

I wrote this book out of the conviction that, as important as the bioscientific dimension is, end-of-life care must redouble its efforts to attend to those other dimensions, too. I envisioned this book as an overview of current knowledge and practices in psychological, social, and spiritual care at the end of life. I wrote primarily with hospital chaplains and social workers in mind. But all the health professionals involved in terminal care—doctors, nurses, hospital chaplains, parish-based clergy, social workers, clinical psychologists, and others—should find new information here they can use in attending dying patients and their survivors. I certainly did in researching the book. Even patients and survivors may find information they can use. Aware of this potentially broad readership, I tried to avoid technical medical terms and concepts as much as possible. However, whenever I needed to use them, I defined them explicitly.

This book's chapters after the introductory Chap. 1 fall into three groups. Chaps. 2 through 5, present basic information that the nonmedically trained might need to understand the process of medical care. I wrote these chapters because a clergy friend once told me that medical care bewilders the patients and families he pastors in the hospital, and they ask *him* to explain the clinical process. He says he always feels unprepared to do so. These four chapters cover end-of-life pathologic processes and symptoms, doctors' clinical thought processes, patients' risk/benefit assessments of treatment options and their preferences concerning those options, and doctors' prognoses. Even the medically trained including doctors may find these chapters helpful reviews of aspects of care that may have become unthinkingly routine in practice.

Chapters 6 through 14, address specifically the psychological, social, and spiritual dimensions of end-of-life care. These chapters cover advance care planning, proxy decision-making, care of family survivors in general and of family caregivers in particular, cultural aspects of end-of-life care, the "right" time and way to die, beliefs about the death transition and the afterlife, bereavement and grief, and spiritual care by health professionals. This book's last chapter, 15, returns to my point that the bioscientific dimensions of end-of-life care may again be overwhelming the non-bioscientific dimensions. The social and spiritual dimensions are at most risk of neglect. I, therefore, believe that health professionals of all kinds must take steps to reestablish a balance between the bioscientific and the nonbioscientific in end-of-life care. Healthcare researchers should also take up the challenge of addressing the many, still unexplored aspects of the nonbioscientific dimensions of such care.

Each chapter here presents a few key concepts and an illustrative case from real life. This format emphasizes the dynamic interplay between concepts and experiences. Concepts shape our perceptions of reality, and real-life experiences hone our concepts. I occasionally offer my opinions, explicitly labeled, on controversial

points. I have also changed a few details of the cases to promote clarity and concision of the text and to protect the anonymity of my sources. Some readers will notice that all the cases depict adult patients. Because I am an internist, my clinical experience involves only adults. Nonetheless, I believe most of the concepts illustrated by these dying adults also apply to dying children. Each chapter concludes with lists of major points, of a few especially worthwhile references for readers who want to read more, and of all references cited in the chapter.

I sometimes use tables to summarize findings from one article or to compare findings of multiple articles on a topic. The format of these tables will be familiar to frequent readers of the clinical literatures but possibly not to other readers. I have, therefore, explained the main points of each table in the text. Readers who wish may skim the tables and concentrate on the explanations in the text; other readers may wish to examine the tables directly, to check my conclusions, and to draw their own conclusions.

I, of course, did not create this book completely on my own. I needed help from others. My wife, Helen, read and critiqued every chapter. A trained actress and portraitist, she reminded me when the numbers began to overload the text or tables. (I tried to heed her advice to revise out as many numbers as possible, but I did not succeed in satisfying her completely.) She and other immediate family members of mine persevered through the long writing process and encouraged me along the way. Of course, I depended on patients and family members who graciously offered their stories of end-of-life experiences as illustrative cases. In addition, years ago Professor Jonsen took a chance by accepting me—though a traditionally trained, bioscientific-style doctor—as one of his bioethics fellows. He then taught me the rich, multifaceted nature of the human condition during illness. I owe my bioethics career to him. My research colleagues in San Antonio, sociologist Helen P. Hazuda at the University of Texas Health Science Center and anthropologist Josie D. Cortez at the Intercultural Development Research Association, helped nurture many of the ideas in this book over our 30-year interdisciplinary collaboration. And, of course, my new colleagues at Springer assisted in many important ways. Kathy Cacace initiated the idea for this book; Margaret Burns shepherded it patiently through development; and Margaret Moore helped with editing, printing, publicity, and distribution. All these people have my heartfelt thanks.

San Antonio, USA

Henry S. Perkins

## References

1. Clark D. Between hope and acceptance: the medicalization of dying. *BMJ*. 2002; 324(13 April):905–7.
2. Von Gunten CF, Lupu D. Development of a medical subspecialty in palliative medicine: a progress report. *J Palliat Med*. 2004;7(2):209–19.

A Guide to Psychosocial and Spiritual Care at the End  
of Life

Perkins, H.S.

2016, XV, 486 p. 3 illus., 2 illus. in color., Hardcover

ISBN: 978-1-4939-6802-2