

Handbook of Thanatology

2nd edition

The essential body of knowledge for
the study of death, dying, and bereavement

David K. Meagher and David E. Balk, Editors



Association for Death Education and Counseling®
The Thanatology Association®

www.adec.org



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Introduction to the Handbook of Thanatology

The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement

1st Edition

Thanatology—the study of death and dying—at its core centers on the whole person. Holistic knowledge and holistic practice intertwine in our interdisciplinary efforts. If ever there was an arena requiring that the research-practice gap be bridged, surely it occurs where thanatologists engage with persons dealing with human mortality. Mastering the complex, multidisciplinary arena that is thanatology is a task, however, beyond human capability.

As in all arenas of scholarship and practice, thanatology too has become more vast than any one individual can be expected reasonably to master. The Association for Death Education and Counseling (ADEC)—*The Thanatology Association*—sought to develop a comprehensive resource covering the fundamental and foundational knowledge in thanatology, while acknowledging that no one person can ever know all there is to know in this complex field. As one of the oldest interdisciplinary professional organizations in the field of dying, death, and bereavement, ADEC is dedicated to promoting excellence and recognizing diversity in death education, care of the dying, grief counseling, and research in thanatology. Based on quality research and theory, the association provides information, support, and resources to its international, multicultural, multidisciplinary membership, and through it, to the public. The *Handbook of Thanatology* is just one of these essential resources.

To find out more about the structure of the handbook and how it came to be, see Certifications in Thanatology on page ix. This is not the be-all and end-all of thanatology resources; ADEC expects to release a revised edition of the *Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement* in years to come, as our vast field continues to grow.

David E. Balk
Editor-in-Chief, *Handbook of Thanatology*
Professor, Brooklyn College of the City University of New York
February 8, 2007

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Introduction to the *Handbook of Thanatology:* *The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement* 2nd Edition

The Body of Knowledge (BOK) Matrix on page xii – xiii of this edition reflects how the basic knowledge of the field of death education, counseling, and research has evolved since the first edition of the *Handbook of Thanatology*. The goal of this edition is to provide substantive content to reflect this evolution and serve as a major resource for those preparing to engage or already professionally engaged in the field.

As in the first edition, the contributors for this edition come from a variety of professional fields: counseling, education, administration, and research. They address a number of topics, many of which include recent controversies; thus, the reader will receive a variety of perspectives from differing viewpoints. Significant changes have occurred within the legal, medical, and ethical arenas with regard to the treatment of the terminally ill and the rights of individuals to actively participate in the decisions around their care and the care of their loved ones. Research has revealed more information about how we humans deal with our own death and the death of our loved ones. Medical advances have resulted in changes in the way we treat the dying. In addition, with the improvements made in organ transplant technology, our ability to prevent death in others has enhanced. Our knowledge of the psychological and emotional responses to traumatic death has also increased our ability to provide immediate and long-term support to affected individuals.

The 21st century may be considered the digital age. To address the impact the Internet has had on death education, grief counseling, and research and in addition to a discussion of this topic in two revised chapters (*Historical and Contemporary Perspectives on Death Education* and *Resources and Research in Thanatology*), we have added a new chapter (*Thanatology in the Digital Age*) to focus solely on this issue.

This edition goes beyond the borders of the United States and Canada. A new international perspective is included with the additions of chapters dealing with issues and programs from Ireland and Israel.

The Editors:

David K. Meagher
Professor Emeritus
Brooklyn College, CUNY
October 1, 2012

David E. Balk
Professor
Brooklyn College, CUNY

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Certifications in Thanatology: How the *Handbook of Thanatology* Can Assist

The Association for Death Education and Counseling (ADEC) envisions a world in which dying, death, and bereavement are recognized as fundamental and significant aspects of the human experience. The association, ever committed to being on the forefront of thanatology (the study of death and dying), provides a home for professionals from diverse backgrounds to advance the body of knowledge and promote practical applications of research and theory. In addition, ADEC offers a two-level certification program for thanatology professionals. This program protects the public by creating a standard for thanatology practice while helping professionals develop and demonstrate their mastery of knowledge of thanatology and thanatology-related issues.

ADEC offers Certification in Thanatology (CT) and Fellow in Thanatology (FT), the details of which can be found at <http://www.adec.org>. *Certification in Thanatology* is a foundation certification that enhances the professional designation established by the academic discipline of each certificate holder. It recognizes the specific educational background in dying, death, and bereavement. Thus, a counselor/therapist or educator is defined by his/her education and work experience. The certification will note the special educational training in the field. The *Fellow in Thanatology* certification is an advanced professional certification for thanatology professionals. It recognizes practitioners and educators in the discipline of death, dying, and bereavement who have met specified knowledge requirements measured through a standardized testing process, and who demonstrate advanced levels of competency in teaching, research, and/or clinical practice through a professional portfolio. Recipients of ADEC certification are required to undergo the recertification process every 3 years.

This *Handbook of Thanatology* emerged as ADEC members serving on the Credentialing Council, the Body of Knowledge Committee, and the Test Committee reflected on efforts to put into operation a reliable and valid exam measuring knowledge considered foundational to thanatology. The structure of this handbook comes directly from the in-

spired efforts of the Body of Knowledge Committee, chaired by Carol Wogrin, in a 2005 two-day winter meeting during which six categories considered fundamental to thanatology were identified. They are:

Category Definitions

Dying: the physical, behavioral, cognitive, and emotional experience of living with life threatening/life limiting illness, caring for the terminally ill, the dying process, and the experience of death

End-of-Life Decision Making: the medical, legal, ethical and interpersonal choices, decisions and behaviors of individuals, families and professionals as life nears its end, that are often associated with a terminal illness

Loss, Grief and Mourning: the physical, behavioral, cognitive, and emotional experience of and reactions to loss, the grief process, as well as rituals and practices surrounding grief

Assessment and Intervention: information gathered, decisions made, and actions taken by professional caregivers to determine and/or provide for the needs of persons who are dying, their loved ones, and bereaved individuals

Traumatic Death: a death that occurs in a manner that is unanticipated, shocking, or violent; may be inflicted, self-inflicted or unintentional

Death Education: formal and informal methods for acquiring and disseminating knowledge about dying, death, and bereavement

Indicator Descriptors

Cultural/Socialization concerns the effect of diverse cultural and social influences on the experience of death and loss.

Religious/Spiritual addresses the relationship that religious and spiritual belief systems have on the reaction to and coping with dying and bereavement.

Professional Issues deal with the factors that affect professionals' training, abilities and responsibilities in providing care to persons who are dying or bereaved.

Historical Perspective views the historical context, developments, and theoretical paradigms that influenced the death experience and in the development of the field of thanatology.

Contemporary Perspective provides the theoretical perspective, factual context and other factors which have influenced the current perspectives on the death experience and the field of thanatology.

Life Span considers the developmental perspectives on death and dying from the prenatal period to old age.

Institutional/Societal relate to the social organizations and institutions beyond the individual and family that affect the experience of dying, death, and bereavement.

Family and Individual addresses the social, cognitive, physical, interpersonal, and emotional encounters, theories and interpretations of dying, death, and bereavement from the standpoint of one's position within the group of people sharing a relational bond, commitment and who define themselves as family.

Resources and Research involves materials, organizations and groups of individuals who study and facilitate the acquisition of knowledge. Moreover, resources involve the ideas and materials based upon the findings of empirical research and theoretical synthesis that add to the knowledge base of thanatology.

Ethical/Legal pertains to the aspects of dying, death or bereavement that concerns the principles of justice, fairness, and the determination of ethically appropriate options. Legal issues refer to the articulated laws of a society that pertain to thanatology.

The six categories and ten indicators form the Body of Knowledge (BOK) Matrix reproduced on the next two pages. The BOK Matrix is copyrighted by the Association for Death Education and Counseling. The examples in the various cells of the BOK Matrix are illustrative of topics considered probable when categories and indicators intersect. For instance, in the cell with the category Traumatic Death and the indicator Religion and Spirituality, you will see the illustrative examples of "meaning reconstruction" and "rituals." The topics in the BOK Matrix presented below are not considered exhaustive.

As early as July 2003 the Test Committee floated a proposal that ADEC commission its own book on the material considered foundational knowledge in thanatology. After much discussion the current structure for the book got strong endorsement: to write separate chapters using a category-by-indicators focus. Thus, there would be a chapter on culture, socialization, and dying; one on religion, spirituality, and dying; and so forth through all the categories and indicators within the BOK Matrix. After some reflection, the editors decided two indicators (professional issues, resources and research) deserved more treatment that would cut across BOK categories (in contrast to the other chapters that focus on a BOK category by a specific indicator).

What you have in your hands is the product of those efforts. For those interested in thanatology certification, this book is a must-read and will continue to be a valuable resource for your practice.

Body of Knowledge (BOK) Matrix

Indicators										
Categories	Cultural/ Socialization	Religious/ Spiritual	Professional Issues	Historical Perspectives	Contemporary Perspectives	Life Span	Institutional/ Societal	Family and Individual	Resources and Research	Ethical/ Legal
Dying	perspectives on dying, health care interactions, family roles	facing death, rituals, meaning, suffering, impact on treatment decisions, afterlife, legacies	self care, boundaries, compassion fatigue, burnout, attitudes toward dying	hospice, causes and patterns of death in Western societies, influential theories	global causes and patterns of death and lifestyle choices, gender issues, impact of technology, influential theories, death attitudes, role of complementary/alternative therapies	normative developmental tasks, developmental concepts of death, special populations	hospice, palliative care, impact of politics, interacting with the health care system, special populations	gender roles, communication, cultural impact on family roles, family history, coping strategies	current significant research findings, organizations and journals, media and internet	allocation of resources, ethical principles, legislation/ medical practice
End-of-Life Decision Making	advance care planning, ethnic issues, values and attitudes, gender	advance care planning, values and attitudes, beliefs and doctrines, suffering, sanctity of life, quality of life	communication, understanding patient's rights	landmark legal cases, attitudes toward final disposition, evolution of advance care planning	options and choices, impact of medical technology, impact of media and Internet	impact of age on decision making, determining competency to make decisions	advance care planning, health care legislation, public/mass media and political impact on decision-making	advance care planning, treatment decisions, communication, family systems	media and Internet, professional organizations, current significant research findings	principles of medical ethics, advance directives, landmark cases, legal planning, decision making processes
Loss, Grief, and Mourning	factors affecting experience of and expression of grief, impact on mourning practices	meaning making, impact on mourning practices	burnout, compassion fatigue, awareness of personal loss history, coping strategies, self assessment, self care, boundaries, clinical competency	influential theories, post-death activities	influential theories and models, post-death practices, media and Internet, intervention strategies	impact of developmental stage on loss experience, specific types of loss and impact on grief and mourning	media and Internet, school/workplace grief, public deaths, political systems	family life cycle, communication, impact of illness trajectory, grief styles, normative grief responses, impact of type of loss	empirical research on current theories, research on effectiveness of intervention	ethics and working with the bereaved, legal aspects of death

Assessment and Intervention	advance care planning, cultural competence, communication, meaning of death	components of spiritual assessment, interventions, facilitating integration of meaning and value of one's life	appropriate components of assessments, communication, professional liability and limitations, determining appropriate interventions in concert with evidence and client characteristics, professional responsibilities	changes in determination of death, intervention theories prior to 1990	current assessment models, current therapeutic strategies, controversy about efficacy of interventions, complicated grief, gender considerations, pathologizing of grief	developmental considerations	impact of death system, impact of societal infrastructure, contributions of grief support services	family systems theory, gender issues, assessment of risk factors for complicated/prolonged grief, appropriateness of specific interventions	evidence of effectiveness of assessment and intervention, community programs	determination of death, informed consent, ethical principles, legal parameters around death, professional responsibilities
Traumatic Death	cause of death, meaning making, advance care planning, ethnic issues, values and attitudes, gender	meaning making, rituals, impact of religion	appropriate training, professional response, commemorative activities, vicarious traumatization	previous major traumatic occurrences	recent/anticipated future traumatic occurrences, impact of communication systems, organ and tissue donation, current approaches	death patterns, issues specific to each developmental phase	meaning making, role of the media and Internet, types of infrastructure, traumatic deaths, impact on specific populations	impact on experience of grief, types of traumatic deaths, coping strategies, individual differences, vicarious traumatization, social support	major national organizations, current significant research findings	criminal justice system, impact on larger society, ethical intervention issues
Death Education	different death systems, diverse views about death	diversity of religious beliefs, diversity of meaning making, diversity of spirituality	evaluation of knowledge, criteria for an effective educator, methods, training specific to parameters of practice, media and Internet	attitudes towards death, history of thanatology as a discipline, historical eras	advance care planning, influence of media and the Internet, social concerns, components of death education	teaching across the life cycle, issues specific to each developmental phase, impact of life transitions	influence of media and Internet, varied educational settings, impact of larger systems, military	formal, informal	types of resources, understanding the research, importance of evidence-based practice, certification, professional organizations	impact of legal system on death, understanding a professional code of ethics, applying principles of ethics

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List of Contributors

David E. Balk is a professor in the Department of Health and Nutrition Sciences at Brooklyn College where he directs graduate studies in thanatology. He wrote *Helping the Bereaved College Student*, which Springer Publishing Co. published in 2011. He was editor-in-chief of the first edition of ADEC's 2007 publication *Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement*.

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Donna M. Corr, RN, MS, took early retirement as professor of nursing, St. Louis Community College at Forest Park. With her husband Charles, the Corrs' publications include 40 books and booklets, along with more than 100 articles and chapters in professional journals in the field of death, dying, and bereavement. Their most recent book is the seventh edition of *Death & Dying, Life & Living* (Belmont, CA: Wadsworth, 2013).

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Kenneth J. Doka, PhD, is a professor of gerontology at the graduate school of The College of New Rochelle and senior consultant to the Hospice Foundation of America. A prolific author, Doka has written or edited 30 books and more than 100 articles and book chapters. Doka is editor of both *Omega: The Journal of Death and Dying* and *Journeys: A Newsletter to Help in Bereavement*. Doka was elected president of the Association for Death Education and Counseling in 1993. In 1995, he was elected to the board of directors of the International Work Group on Dying, Death, and Bereavement and served as chair from 1997-1999. The Association for Death Education and Counseling presented him with an Award for Outstanding Contributions in the Field of Death Education in 1998. He is a licensed mental health counselor and ordained Lutheran clergyman.

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Richard B. Gilbert, PhD, DMin, CT, has been an active member of the Association for Death Education and Counseling since the early 1980s. He has served in many posts, including the board, certification chair, co-chair of the conference in Albuquerque, and a frequent presenter. He was awarded the ADEC Distinguished Service Award at the Miami conference (2011). He retired from hospital chaplaincy and related ministries in 2007. He continues speaking, teaching, and writing. A new edition of his book, *Heartpeace* (Centering) was just released, and, in press with Baywood, *Living and Loss: The Interplay of Intimacy, Sexuality and Grief*, co-edited with Brad DeFord. Two other books are in the formative stage.

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Dennis Klass, PhD, is a professor emeritus living on Cape Cod. He earned a doctorate from University of Chicago where began his work in thanatology as an assistant in Elisabeth Kübler-Ross' famous seminar. He is on the editorial boards of *Death Studies* and *Omega, Journal of Death and Dying*. Klass was the professional advisor to the St. Louis Chapter of Bereaved Parents for more than twenty years. In that role he did a long-term ethnographic study of parental bereavement. Over the last two decades Klass has turned his research toward the cross-cultural study of grief. He is the author of *The Spiritual Lives of Bereaved Parents* (Brunner/Mazel, 1999) and *Parental Grief: Resolution and Solace* (Springer, 1988). He is the coauthor of *Dead but not Lost: Grief Narratives in Religious Traditions* (AltaMira, 2005) and co-editor of *Continuing Bonds: New Understandings of Grief* (Taylor Francis, 1996). He has written more than 50 articles or book chapters.

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David K. Meagher, EdD, CT, professor emeritus, Brooklyn College-CUNY, is the founder of its Thanatology Graduate Studies Program at Brooklyn College. He has served on the advisory boards of two hospice programs and ElderPlans' Widowed Support Service in New York. A recipient of ADEC's 2004 Death Educator Award, David is a past president of ADEC. He has also served as consultant to the Office of the Medical Examiner of Suffolk County, NY, the Floating Hospital of NY, the NFDA, and the NYC Department of Education. He is the author of *Zach and His Dog: A Story of Bonding, Love, and Loss for Children and Adults to Share Together*. Meagher was an associate editor of the first edition of the *Handbook of Thanatology* and is the coeditor of the second edition.

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Blair Sumner Mynatt, MS, NCC, is a doctoral candidate in counselor education at the University of Tennessee. While a student, she obtained graduate certificates in qualitative research in educational settings; evaluation, statistics, and measurement; and gerontology. As part of her gerontology certificate, she completed over 600 clinical hours in the hospice and assisted-living settings. Her clinical experience includes grief work with adults and children (and their families) with intellectual disabilities and autism. She also has extensive experience working with children with grief issues in the school setting. Blair completed a LEND/UCEED traineeship with the University of Tennessee College of Medicine Boling Center for Developmental Disabilities. Blair is an active conference presenter and received numerous leadership awards while a student. She served as the student representative on the American Counseling Association Governing Council and was selected as a Chi Sigma Iota International Honor Society Leadership Intern.

Robert A. Neimeyer, PhD, is professor in the Department of Psychology, University of Memphis, where he also maintains an active clinical practice. Since completing his doctoral training at the University of Nebraska in 1982, he has published 25 books, including *Techniques of Grief Therapy: Creative Practices for Counseling the Bereaved and Grief and Bereavement in Contemporary Society: Bridging Research and Practice* (both with Routledge), and serves as editor of the journal *Death Studies*. The author of nearly 400 articles and book chapters, he is currently working to advance a more adequate theory of grieving as a meaning-making process, both in his published work and through his frequent professional workshops for national and international audiences. Neimeyer served as a member of the American Psychological Association's Task Force on End-of-Life Issues and chair of the International Work Group for Death, Dying, and Bereavement. In recognition of his scholarly contributions, he has been granted the Eminent Faculty Award by the University of Memphis, made a fellow of the Clinical Psychology Division of the American Psychological Association, and given the Research Recognition and Clinical Practice Awards by the Association for Death Education and Counseling.

Kevin Ann Oltjenbruns, PhD, was a long-time faculty member (31 years) in the Department of Human Development and Family Studies at Colorado State University where she served as vice provost for undergraduate studies for 3 years prior to her retirement in June 2005. She served in many other administrative roles at the university, including serving as the associate dean in the College of Applied Human Sciences. Currently, she is serving as a codirector of the Osher Lifelong Learning Institute through the Division of Continuing Education at Colorado State University. Oltjenbruns's research and teaching focus was in the area of grief and loss. She co-authored a textbook entitled *Dying and Grieving: Lifespan and Family Perspectives* and also wrote numerous articles and chapters, focusing primarily on various issues related to developmental stages and grief. In addition to many other community volunteer activities over the years, Oltjenbruns has been involved with Hospice of Larimer County (in Northern Colorado) and is a frequent guest speaker on topics related to grief. Oltjenbruns served as the editor of ADEC's *The Forum* newsletter for 3 years and was honored as ADEC's Death Educator of the Year in 2006.

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Ester Shapiro, PhD, (aka Ester Rebeca Shapiro Rok) is associate professor of psychology, University of Massachusetts and research associate, Gaston Institute for Latino Research and Public Policy. A Cuban Jewish Eastern European immigrant, she is committed to helping all families make the most of their opportunities for improving life chances even when facing adversity, death, and loss. Her teaching, research, and practice apply cultural and ecosystemic approaches to understanding and facilitating positive outcomes during family life cycle transitions by reducing stressors and mobilizing resources linking individual, family, and social/community change. She wrote *Grief as a Family Process: A Developmental Approach to Clinical Practice* (Guilford, 1994), is completing *Promoting Grief and Growth: Family and Cultural Contexts in Bereavement Care*, and was coordinating editor of *Nuestros Cuerpos Nuestras Vidas* (Seven Stories 2000), the Spanish transcultural adaptation of *Our Bodies, Ourselves*. She has published and

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Simon Shimshon Rubin, PhD, is chair of the clinical psychology program and professor of psychology at the University of Haifa in Israel. He is founder and director of the International Center for the Study of Loss, Bereavement and Human Resilience at the University of Haifa. Previously, he directed the postgraduate program in psychotherapy there. Rubin has lectured and published extensively nationally and internationally on matters related to bereavement, ethics, and psychotherapy. His work addresses the applied, clinical, research, and theoretical aspects of these fields. His most recent book, *Working with the Bereaved: Multiple Lenses on Loss and Mourning*, was written with R. Malkinson and E. Witztum and was published in 2012 by Routledge. Previously, they published *Loss and Bereavement in Israel* in 1993 and *Traumatic and Nontraumatic Loss and Bereavement: Clinical Theory and Practice* in 2000.

Anne M. Smith, MA, received her master's in community health, thanatology from Brooklyn College, CUNY. She has been working in the field of hospice and bereavement for the past 15 years. In addition to her work as a bereavement counselor at an inpatient hospice, she is currently facilitating bereavement groups at a local hospital and teaching a thanatology course at Ramapo College of New Jersey. She also works with her husband, a veterinarian, to support and educate clients regarding end-of-life issues for pets and pet bereavement.

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Robert G. Stevenson is currently an associate professor in the Counseling Program of the School of Social and Behavioral Sciences at Mercy College, NY. He has published more than 60 journal articles and book chapters and edited/authored several books. Two of his most recent publications are *Perspectives on Violence and Violent Death* and *What Will We Do? Preparing a School Community to Cope With Crises*. His degrees include a bachelor's (College of the Holy Cross), master's (Montclair State University), and both

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Dying

Introduction to Part 1, Chapters 1 – 6

[Chapters 1](#) through [6](#) focus on dying. The Body of Knowledge defined this major category of thanatology knowledge in this way: **the physical, psychosocial, and spiritual experience of facing death, living with terminal illness, the dying process, and caring for the terminally ill.**

The six chapters of [Part 1](#) focus on dying in terms of these indicators: culture and socialization, religion and spirituality, historical and contemporary perspectives, life span issues, the family and larger systems, and ethical and legal issues. Five chapters were revised from the chapters that appeared in the first edition, and in the case of [chapter 6](#), the contributor wrote a wholly new chapter.

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Chapter 1

Culture, Socialization, and Dying

Charles A. Corr and Donna M. Corr

This chapter examines some cultural and social aspects related to persons who are dying or closely approaching death, as well as the care they are offered. The challenge we face is that there are myriad cultural and social variables that may affect dying in any historical and social situation because historical circumstances differ across time and in different communities. Accordingly, societal death systems change in their responses to specific challenges. More importantly, because dying is not the whole of anyone's life, it is critical to keep in mind that *dying persons are living human beings*. Dying is a special situation in living; it cannot properly or fully be understood without taking account of the entirety of a person's life, both individually and within the social systems in which that person is living.

Cultural Factors That Affect Dying

Every human being is born into and raised within a context in which cultural, social, religious, and ethnic factors influence his or her life. As such, these variables, which we subsume here under the broad heading of "cultural factors," affect each individual's views of and interactions with dying and death. This cultural influence is true whether the individual accepts or rejects the acculturation that he or she receives, since even in rejection those cultural factors provide a benchmark against which the individual defines and conducts his or her life.

One way to understand the various factors addressed in this section is to think of culture as "a unified set of values, ideas, beliefs, and standards of behavior shared by a group of people; it is the way a person accepts, orders, interprets, and understands experiences throughout the life course" (Thomas, 2001, p. 40). Clearly, in the United States and in most other countries, there are many, often quite diverse, cultural groups. Coming to know something about those cultural groups helps to improve appreciation of ourselves, other people, and our society as a whole.

For example, if we think for a moment about what we know concerning religious

differences in beliefs, attitudes, and practices, we can easily recognize differences between various Christian denominations, between orthodox and reform Jews, and between Sunni and Shia Islamic groups. At the same time, it is all too easy to develop stereotypes around religious and cultural differences. For example, we may perceive members of one religious or cultural group as highly expressive and demonstrative in ways they face loss, while others may be viewed as much more reserved and even stoic. This observation may be true as a generalization about the group, but is it also true of every member of that group? In other words, are we settling for superficial stereotypes in what we think about cultural groups and their diverse members?

So our task is to be equally sensitive both to differences between cultural groups and to diversity within those groups. For this reason, it is notoriously difficult to speak in a general way about how cultural factors influence human beings and what results they produce. What is needed is an effort to enter into specific cultural groups and see how they address issues related to dying, an effort something like the one undertaken by the editors of a five-volume series about *Death and Bereavement Around the World* (Morgan, Laungani, & Palmer, 2002-2009). Our project in this chapter will inevitably be on a much more limited scale.

In this chapter, we focus on selected examples of ways in which cultural factors bear on experiences of dying. Among many possible examples, these include:

- Communication within family or cultural groups and between those groups and outsiders
- Decision making within some family and cultural groups
- Issues about who should be primarily responsible for care of a dying person
- Distrust by members of cultural groups with regard to the larger social system, its health care institutions, and some health care providers

Concerning *communication*, Thomas (2001, p. 42) has written that, "Communication about end-of-life issues is the key to understanding and making rational decisions." Accordingly, there have been numerous reports that maintaining control over communication is an important issue for many Asian Americans and some members of other cultural groups (e.g., Doka & Tucci, 2009; Tanner, 1995; Tong & Spicer, 1994). For example, members of such communities may be quite restrained in communicating to health care providers what they are experiencing when they are in distress and dying. Also, some family members may place a high priority on not telling dying persons that they are dying. Health care providers who do not share such values or who lack cultural sensitivity may become frustrated when they are caring for a dying person from such a cultural group.

Closely related to attitudes associated with communication are those related to *decision making*. Because patriarchal and hierarchical structures are prevalent in some cultural groups, in such groups it is often the oldest male or at least an older member of the family who is expected to make decisions about the care of dying family members (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Braun, Pietsch, & Blanchette, 2000).

To outsiders, this practice may appear to deny or at least infringe upon the autonomy of the ill person.

Another significant issue in which cultural factors play an important role has to do with *who should care for a dying person*. In contemporary American society, the provision of such care is often primarily assigned to outsiders—to staff and volunteers in hospitals, long-term care facilities, and hospice programs. Studies of certain Hispanic cultural groups (e.g., Cox & Monk, 1993; Delgado & Tennstedt, 1997; Gelfand, Balcazar, Parzuchowski, & Lenox, 2001), however, have noted that this role is primarily and insistently held within the family and there most often assigned to female members.

Distrust has many causes and is often quite deep-seated. For example, among African Americans some have traced it back to the general implications of slavery and particularly to the Tuskegee study conducted by the United States Public Health Service. Begun in 1932, the study initially offered the only known treatments at the time to poor African-American sharecroppers in Alabama with syphilis. Tragically, participants were eventually allowed to go untreated until they died in order to study the natural progress of the disease. This research design occurred even after penicillin became available in the mid-1940s and was shown to be effective in treating syphilis. The study was not halted until it was exposed in the press in 1972 (Jones, 1992; Washington, 2006). More recent reports have addressed ongoing racial injustice in health care (e.g., Freeman & Payne, 2000; Geiger, 2002). As a result, many African Americans believe the health care they receive is less adequate than that offered to Caucasian Americans (Tschann, Kaufmann, & Micco, 2003; Waters, 2001).

These issues affecting dying persons and care of the dying are intertwined with ways in which individuals and members of groups in our society view the importance of family, the role of religion, and the importance of being present at a death. They also influence other matters, such as whether or not persons are willing to making advance plans for end-of-life treatment, to consider opportunities for organ donation, or to take part in physician-assisted suicide.

Death Anxiety and Concerns That Affect Dying

Much attention in recent years has been given to the concept of death anxiety and its measurement (e.g., Neimeyer, 1994; Neimeyer, Wittkowski, & Moser, 2004). For example, many reports suggest that women report higher death anxiety than men in our society, while older adults appear to report less death anxiety than some younger persons. It has also been argued that death anxiety is a complex concept, one that varies with both demographic and personality factors, as well as with life accomplishments and past or future regrets (Tomer & Eliason, 1996).

Further, death-related attitudes may reflect very different concerns and responses such as those focused on:

- *My own dying*: Will it involve a long, difficult, painful, or undignified dying process, especially in an alien institution under the care of strangers who might not respect

my personal needs or wishes—if so, I might wish that my dying would occur without any form of distress or prior knowledge, and in my sleep, or perhaps I might take deliberate action to prepare an advance directive or to seek out opportunities for physician-assisted suicide (sometimes called “death with dignity” or “aid in dying;” Corr, 2012), thereby hoping to avoid unacceptable ways of experiencing my dying; by contrast, concerns about my own dying might lead me to wish to avoid a sudden, unanticipated death, allowing time to address “unfinished business,” bid farewell to loved ones (Byock, 2004), and “get ready to meet my Maker.”

- *My own death*: Will it release me from hardships and suffering, or will it involve losing the life and everything it involves that has been and still is so important to me?
- *What will happen to me after my death*: Am I anxious about the unknown and fearful of judgment or punishment after death, or am I anticipating a heavenly reward, a passage to a better life, or a reunion with someone who had died earlier?
- *The bereavement of someone I love*: Am I mainly concerned about the burdens that my illness and dying are placing upon those whom I love and/or am I worried about what will happen to them after I am gone?

Dying in Our Social System: Once Upon a Time

In times past in the United States of America and in many other developed countries around the world, what Glaser and Strauss (1968) identified as *dying trajectories* were relatively brief and largely predictable experiences. Mainly caused by communicable diseases, dying typically involved clear and recognizable symptoms such as fever, diarrhea, nausea, vomiting, or muscle ache. Family members, friends, and those professionals who might have been available would have been able to recognize that individuals displaying these symptoms were seriously ill. On the basis of past experiences with similar patterns of disease, it could often be predicted whether or not an individual afflicted in these ways would recover or would die and possibly also when the outcome would be known.

Care given to such individuals would largely have been supportive in nature, offered in the hope that the body would heal itself and concerned not to interfere in that process. This care would likely have focused on providing a place to rest, shelter from the elements, a cool cloth to wipe a feverish brow, and nourishing food (“chicken soup”). Various forms of spiritual intercession would often have accompanied it. Many fortunate individuals would have been cared for at home and by family members. Hospitals likely would not have been available. Even when they were, they often took the form of charitable institutions (almshouses) with large, crowded wards that were typically dark, stuffy, unpleasant, and even life threatening since they threw together many different types of people with very different disabilities and often contagious conditions.

As Western culture became more urbanized, hospitals began to change. During the latter half of the 19th century, a biomedical model emerged that viewed disease as involving specific entities and predictable causes. Therapy became intended to “fix” malfunctioning parts of the human body. Specialization in carrying out therapeutic tasks

became the norm. A division of labor came to characterize both health care providers and health care institutions. In particular, hospitals—now often called “medical centers” or “health centers”—came to focus on acute care in which scientific medicine sought to cure disease. A paradoxical result of this new focus on hospital-based, acute care is that within the very institutions in which nearly half of all Americans now die death often began to be perceived as involving a kind of failure.

Following passage of the Social Security Act of 1935, which added federal funding to the personal resources of individuals and their relatives, health insurance, and retirement packages, long-term care facilities began to be developed. These long-term care facilities (often called “nursing homes”) filled the need for chronic care as families had often become small, nuclear groupings in which individuals frequently lived at a distance from their kin instead of extended clusters living nearby in the same community. Chronic care became especially important as average life expectancy increased, individuals were no longer able to work or had decided to retire from work well before their deaths, and many required assistance in caring for themselves and in performing activities of daily living as they lived out the last years of their lives.

Many long-term care facilities in our society provide excellent services, but some have been hesitant when requirements for chronic care evolved into needs for end-of-life care. Some coped by transferring residents to acute care hospitals shortly before their deaths, while others tried to make do or to develop their capacities to care for dying persons. However that may be, approximately 22 percent of all Americans currently die in long-term care facilities.

Recent Efforts to Change Social Systems and Improve Care for the Dying

During the early decades of the second half of the 20th century, new perspectives were advanced concerning the situation of those who were coping with dying, the nature of pain when one is dying, and appropriate therapeutic regimes for such persons. Above all, these new perspectives questioned how the social organization of programs serving those who are coping with dying affected the care provided and they stressed the value of holistic, person-centered care and interdisciplinary teamwork. That led to the development of the hospice movement, heightened interest in palliative care, and efforts to apply hospice principles in hospitals, long-term care facilities, and other settings.

Unfortunately, there is evidence that these efforts have not benefited all who are dying in our society, especially those in the best of our acute care institutions. For example, the research project called SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments; SUPPORT Principal Investigators, 1995) examined end-of-life preferences, decision making, and interventions in a total of 9,105 adults hospitalized with one or more of nine life-threatening diagnoses in five teaching hospitals in the United States. The 2-year first phase of the study observed 4,301 patients and documented substantial shortcomings in communication, overuse of aggressive cure-

oriented treatment at the very end of life, and undue pain preceding death. The 2-year second phase of the study compared the situations of 4,804 patients randomly assigned to intervention and control groups with each other and with baseline data from Phase 1. Physicians with the intervention group received improved, computer-based, prognostic information on their patients' status. In addition, a specially trained nurse was assigned to the intervention group in each hospital to carry out multiple contacts with patients, families, physicians, and hospital staff in order to elicit preferences, improve understanding of outcomes, encourage better attention to pain control, facilitate advance care planning, and enhance patient-physician communication.

The SUPPORT study used multiple criteria to evaluate outcomes, such as the timing of written do not resuscitate (DNR) orders, patient and physician agreement (based on their first interview) whether to withhold resuscitation, the number of days before death spent in an intensive care unit either receiving mechanical ventilation or comatose, the frequency and severity of pain, and the use of hospital resources. Results were discouraging. Phase 2 intervention "failed to improve care or patient outcomes" (p. 1591) and led to the conclusion that "we are left with a troubling situation. The picture we describe of the care of seriously ill or dying persons is not attractive" (p. 1597).

We are left to hope that the hospice movement—consisting of an estimated 5,000 programs that cared for 1.58 million dying persons in 2011 (almost 42% of all Americans who died that year), nearly 67% of whom were able to die in a place they called home (NHPCO, 2012)—and the related palliative care movement will eventually have a more favorable influence on care of the dying in hospitals and long-term care facilities.

Some Concluding Thoughts

Dying persons have always been members of the human community and responsibilities for their care have always been with us. In the preface to her celebrated book, *On Death and Dying* (1969), Elisabeth Kübler-Ross reminded readers that we should pay attention to dying persons and to all who are coping with dying for three reasons (Corr, 2011):

1. They are *still alive* and often have "unfinished business" they want and need to address.
2. We need to *listen actively* to them in order to identify with them their tasks and needs so that we can be effective providers of care.
3. They have *much to teach us* about our shared humanity and the final stages of life with all its anxieties, fears, and hopes.

To say this message in another way, we pay attention to dying persons because they are living human beings, because we want to improve our society for all its members, and because we want to have better systems in place to care for ourselves and for our loved ones when we face our own dying and death at the end of life.

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