PSYCHOSOCIAL ASPECTS OF DEATH AND DYING

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Transitions in Dying and Bereavement: A Psychosocial Guide for Hospice and Palliative Care, by the Victoria Hospice Society, Moira Cairns, Marney Thompson, and Wendy Wainwright. Health Professions Press, Baltimore, MD, 2003, 394 pp., $36.95 (paper).

As America moves through each new decade, we can expect an increasing cultural denial of aging and dying. This defiance of aging is evidenced by the growth of anti-aging potions, plastic surgery, and Botox treatments. The popularity of embalming (mummification) and cosmetic “restoration” of bodies that “lie in state” in “slumber rooms,” processed by “funeral directors,” or the ultimate form of denial—“cryonics”—could be related to an American cultural aversion to death. In summary, few people age, die, and are buried in America without experiencing some form of chemical “restoration.”

As we review the three books on psychosocial aspects of death and dying, we must not forget the movement from the sacred to the profane—the cultural growth of materialism in America. One cannot separate the elderly from the narcissistic culture that devalues old age (Lasch, 1979). Some sociologists have long warned us of the concomitant growth in America of secularization, modernization, and urbanization. Death denial often accompanies secularization. Elizabeth Kubler Ross once called America a “death denying society.” Death is an insult to the materialist, even more degrading than a wrinkled face and being dependent on others—processes that are among the hallmarks of old age. The body of literature on death anxiety among the aged is comprehensively covered in Death Attitudes and the Older Adult: Theories, Concepts, and Applications, edited by Adrian Tomer. Gerontologists should find this book highly useful and informative, filling in a gap in our field by summarizing current research on death attitudes and anxiety among seniors. Death always brings anxiety to a pleasure driven culture, even its old people. For instance, Elder Hostel instructs universities not to offer courses on any death-related topics to seniors. Beyond offering information on the Widowed Persons Service, AARP rarely addresses death or long-term-care issues (e.g., older individuals being put on respirators or tube feeding, laws regarding euthanasia, etc.).

Death Anxiety: The Theories, Empirical Findings, and Issues

Tomer’s book has four parts. The first focuses on theories, models, and concepts that delineate the conceptual gap between gerontology and thanatology. The second part presents empirical findings on death attitudes and anxiety in relationship to old age. Trends and correlates of death anxiety and attitudes as possible causal connections are discussed in this section as well. Part three deals with applied issues surrounding end-of-life decisions made by different ethnic groups of older persons. This section explores such issues as physician-assisted suicides and the attitudes of nurses toward death and hospice care.

There is much deliberation in gerontological circles on the issue of doctor-assisted suicides versus allowing elders to die “naturally.” With relatively new euthanasia laws in Oregon and many negative reactions to such laws by the mainline and fundamentalist Christians, Moslems, and other faiths in the United States, these topics become hot thanatological issues, ready made for gerontological debate or discourse. The fourth part of the book focuses on counseling seniors and the future of death attitudes and aging in the 21st century. Key attention is directed to special coping skills, spirituality, and cultural connections. The “Points to Remember” summary at the end of each chapter is an excellent pedagogical aide.

Religion, Culture, and Death Anxiety

Death attitudes of elders have not been well integrated into the field of gerontology. Although Tomer fails to mention gerontology’s Disengagement Theory, several newer theoretical models that explain how seniors accommodate to death are delineated. Two of them are: Tornstam’s theory of gerotranscendence (Tornstam, 1996) and Carstensen’s socioemotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999). In Tomer and Grafton Eliason’s chapter, “Attitudes about Life and Death: Toward a Comprehensive Model of Death Anxiety,” death anxiety is placed as a dependent variable at the end of a complex web of variables such as beliefs about the self or worldview. In this model, the meaningfulness of death is discussed in terms of types of beliefs about an afterlife. Yet these authors should also consider strength of belief in an afterlife.

Except for psychologist James Keene’s pioneering research (1967; 1968) in which he compared the effects of various world religions on the development of “healthy” personalities in adults, gerontologists have not investigated the unsuspected and differing effects of various world religions on the personalities of older individuals. Moreover, personalities connect to one’s coping mechanisms. How do these variables relate to elders’ attempts to cope with dying and death? Thanatologists have not compared or contrasted the beliefs of various seniors who represent different faiths, nor have they compared or contrasted the abilities of different dogmas of world religions to help their elderly faithful either thwart or increase death anxiety. For example, studies should seek to discern whether there...
are differences in death anxiety between elders representing fundamentalist versus mainline Christian denominations. More important, gerontologists should investigate whether there are significant differences between the dogmas or belief systems of the Baha'i, Buddhist, Protestant and Catholic, Islamic, Hindu, Jewish, and other faiths in their effectiveness in assisting their elderly devotees to cope with or avoid death anxiety. This type of research is ignored in gerontology and thanatology beyond books that offer comparisons of world religions beliefs about death and the afterlife (cf., Johnson & McGee, 2000).

Paul T. P. Wong’s chapter on “Meaning of Life and Meaning of Death in Successful Aging” in Tomer’s volume points out that no one would question Americans’ desires to reduce morbidity and increase longevity. But what about the cultural devaluation of those people who neither achieve nor value these goals? Gerontologists should address the materialist youth-oriented culture of the United States and how its views of attractiveness may have an impact on people who are culturally defined as unattractive (e.g., the old, obese, and chronically ill). Can anything be done to help change the norms?

A chapter by Shannon McCoy and colleagues, “Transcending the Self: A Terror Management Perspective on Successful Aging,” argues that Terror Management Theory (Greenberg, Pyszczynski, & Solomon, 1986) dictates that a senior’s understanding of the inevitability of death is the underlying source from which all other fears—even death anxiety—are ultimately derived. But how does the culture relate to these fears?

The “anxiety-buffer hypothesis” (Greenberg et al., 1992) suggests that to the extent that a psychological structure provides protection to an older person against anxiety, strengthening that structure should reduce one’s proneness to feeling anxiety with regard to reminders of what one is afraid of. Yet, do qualitative differences exist in the strengthening approaches? Therein lies a gap in gerontological literature that this and the book fail to address. Death anxiety research needs to compare the death anxiety variations of elderly believers from exclusivist religions (fundamentalist Christians—Southern Baptists, Churches of Christ, Assemblies of God, etc.) with those from inclusive religions (e.g., United Methodist, Baha’i, Quaker, etc.). What is meant by exclusive is the belief that only a few (e.g., “born again” Christians) people get to Heaven with the vast majority of people going to Hell versus the inclusivist belief that although it may take work, most people will eventually be “saved” or get to Heaven. Would a Baptist elder have more death anxiety if she wasn’t sure she was “saved” (a fundamentalist Christian term foreign to Catholics), knowing that there would be an immediate judgment and she would go directly to Heaven or Hell versus a Catholic elder who knows that as long as she has gone to confession she will earn at least Purgatory—if not Heaven, instead of going directly to Hell to burn forever. In other words, death anxiety could partially be a result of different beliefs.

Robert W. Firestone’s chapter on microsuicide and the elderly is interesting. It is well known that many self-destructive behaviors (e.g., self-denial, substance abuse, refusing to take life-saving medications, etc.) occur among some seniors. The question is how do you get a person to care enough to take care of herself when she is not motivated? As the continuity of theory of aging suggests, not all older people are fixed in their ways. Instead, if they were socialized to be open-minded when they were young they are more likely to remain so when they are old, or if they were closed-minded when they were young they would remain so when they reach old age.

“Death-Related Attitudes and Death Anxiety: A Comprehensive Review,” a chapter by Tomer, points out that death-related attitudes have a cognitive component that connects death to our lives. Research indicates that older persons are more likely to be anxious about death when they have lower levels of ego integrity, a high number of physical problems, psychological problems, lack of religious beliefs (not religious behaviors), or being institutionalized. Those elders that fear death seem to do so because it is unknown, they might fear being punished, they fear a loss of self, or they think of lost opportunities in life.

In an earlier work Tomer and Eliason (1996) proposed a Comprehensive Model of the Death Anxiety Scale that relates death anxiety to three factors: past-related regret, future-related regret, and meaningfulness of death. This scale offers gerontologists a way to measure these phenomena among senior populations. But how do gerontologists help seniors overcome death anxiety? The answer is there are multiple tools and resources that are available, like the following: life reviews, life planning, identification with one’s culture, self-transcending exercises, and religion.

**Older Adults’ Views on Death**

*Older Adults’ Views on Death,* by Victor Cicirelli, arose from his earlier research on end-of-life decisions. This book gives gerontologists a realistic understanding of the key factors that influence the views of elderly populations on death and dying. It looks at the impact of such influences as family relations, religious beliefs, age-related health changes, culture, and personal death meanings. Until this study, research on the meanings of death was focused on views of younger populations. In order to learn about death meanings among elderly populations, this study focused on seniors aged 70–90, the age group most vulnerable to morbidity and death. Thus, how does an elder’s meaning system and fears concerning death either contribute to adjusting (or maladjusting) to the old-age meanings (or lack of meanings) or to fears concerning death contributed to adjustment to old age?

During the shrinking amount of time elders have remaining, recognition of increasing vulnerability to death serves to push some toward achieving unfulfilled life goals. Yet there are others who allow this fact to discourage them from trying to achieve their goals. Regardless of waning time, most elders try to extend
the later portion of their life. Many adopt healthier lifestyles in an attempt to postpone death. Many struggle to live even when they are profoundly sick. Yet some older persons fear being subjected to futile end-of-life treatments that do not restore their health and drain their families emotionally and financially. Although the vast majority of seniors oppose suicide, there are some growing numbers of people who approve of active euthanasia, wanting to avoid becoming a “burden” to their loved ones, a decision that could be culturally influenced.

Cicirelli’s book does an excellent job of exploring elders’ views on the broad topic of death, based on a small empirical study. Each chapter focuses on a particular topic while looking at how elders think and feel. Gerontologists will learn about the sociocultural meanings of death and how individuals’ views of death come about in relation to the society and culture. The meanings of death held by an elder are developed in relation to the institutions of society (e.g., hospitals, hospices, nursing homes, etc.) that influence the persons capacity to function. The book probes into the personal meanings of death, including sociological influences coming from the family system to the larger society (e.g., 9/11’s influence on America). The belief in an afterlife is reported to be the most strongly held meaning. Hence, elders value death as something preferable to infinite life.

Some elders in Cicirelli’s study reported a fear of death, whereas others seem to have removed such fears as they move toward the end of life. “Yet the factors which explain those fears are still not well understood” (p. 150). The older adults were also asked to anticipate what their dying experience might be like. Much in line with our secularization theme, many viewed dying in a figurative rather than literal sense, using the metaphor of sleep to represent death. These seniors did not seem to acknowledge the reality of a “decline in health status, emerging physical symptoms, psychosocial changes during dying, or the physical, social, and emotional needs that may be involved” (p. 189). As the author points out, the fact that these elders did not entertain these thoughts might indicate “some denial of the dying process” (p. 189). Moreover, there was an overall denial of fear of death, and there were no projections about when they might die. Like other literature indicates, strong (subjective or intrinsic) religiosity was correlated with a reduced fear of death among those interviewed.

The results of studying these seniors’ attitudes can be summarized as denial: They see death as simply a happy transition to an afterlife. The dying process will be simple—a painless fading into the sunset or slumber, accompanied by sadness for the survivors. Even if one is in good health it is not desirable to live beyond one’s 90s. But how do their differing theologies and other variables affect such desires? This research did consider contextual factors (e.g., the kinds of housing that elder adults live in, different types of neighborhoods, availability of transportation and services, availability of useful roles for elders, urban or rural areas, and personality factors) that may influence a person’s efficacy and connections to community life. The author concludes, “[O]ne might support and promote the religious beliefs of societal members to a greater extent if they lead to changes in personal meanings of death that reduce the stress on individuals caused by fear of death” (p. 363). We agree with these observations.

**Death Attitudes in Hospice Care**

Probably the best social resource we have for reducing denial of death is the hospice movement. Although denial as a defense mechanism surfaces sometimes in hospice patients and their families, hospice is designed to encourage people to live fully with the knowledge of impending death from a terminal illness. The back cover of *Transitions in Dying and Bereavement: A Psychosocial Guide for Hospice and Palliative Care* describes dying, death, and bereavement as “a rich complex journey of body, mind, and spirit for all involved.” The Victoria Hospice Society, Moira Cairns, Marney Thompson, and Wendy Wainwright have provided readers with such a journey in this book’s descriptions and explanations of stages of dying and palliative care. Their focus is on hospice as a team concept; and the fact that the lead authorship of *Transitions* is attributed to the Victoria Hospice Society rather than to individual authors sets the tone for this thorough, wide-ranging book that describes hospice care throughout stages of dying, death, and bereavement. As the hospice movement in the United States developed in the 1970s it led to a focus on palliative care, including the care of social workers and counselors who have served at Victoria Hospice since it was founded in 1980 and who worked with the authors to develop, write, and review the book. The Victoria Hospice works with more than 800 patients and 1,800 family members each year, and the wealth of experience its workers bring to a discussion of palliative care is enormous (Stoddard, 1978).

With the hope of achieving valuable experiences in facing death for hospice patients, families, and staff, *Transitions in Dying and Bereavement* includes a wealth of information designed to encourage adequate psychosocial care of the dying person and her or his loved ones. From the authors’ perspectives, a “good” death in hospice is one in which the needs and wants of dying individuals and their families are addressed in all their dimensions by their hospice team. People are viewed as having spiritual, emotional, intellectual, social, cultural, interpersonal, and economic components to their lives. In the authors’ view, successful psychosocial care addresses each of these areas at each stage of the dying process and after death.

Among the stated goals of this book are to delineate the aims of hospice counselors, how they can accomplish these aims, and how they can best work as a team with each other, with other hospice staff, and with persons facing death and/or bereavement. These goals are addressed in the book through descriptions of different stages of dying and bereavement. While other books (Reoch, 1996; Little, 1985; Smith, 1997) offer training in more specific skills for caring for dying patients (e.g., techniques for massage, bed changing,
etc.), the focus here is on team members’ roles in psychosocial care as described by different hospice workers. Patient stories are told to describe care practices and issues specific to different cases. Always the goal is to “companion them in their grief and sorrow, looking for opportunities to comfort, reframe their helplessness, and encourage hope” (p. 118).

Transitions in Dying and Bereavement is designed to be a reference or clinical handbook. Ten chapters include case studies, key considerations, team issues, reflective activities, and suggested resources, as well as many other helpful approaches to palliative care. The guiding framework for the book is The Palliative Performance Scale (PPS)—a modification of the 1948 Karnofsky Performance Scale—that Victoria Hospice Society’s medical workers developed in 1995. This modified scale rates a patient’s stages of functioning from 100% (full activity with no sign of disease) to 0% (death) at 10% intervals. It includes components of levels of ambulation, activity and evidence of disease, self-care, intake, and consciousness. Although it does not include a category for death anxiety, the scale can be used to assess the psychosocial impact of each level of functioning for patients in a manner that allows staff members to address specific issues and concerns which patients and families experience as the patient’s health declines. New physical indications and new psychosocial impacts are reviewed for each phase of the dying process.

The PPS is discussed in detail in Chapter 1 and from that point forward provides a way to understand and address the needs of patients and families while giving palliative care. The PPS works beautifully as the guiding framework for the book, with most chapters built around assessing and addressing the transitional stages in the patient’s dying process. This unique approach, with its detailed evaluation of stages, changes, and strategies of assistance, is the primary strength of the book. For additional ease of understanding, a phase model of grief is also included in Chapter 1 in a helpful chart format addressing the transitions family members go through and the needs they have after a death.

Each chapter of Transitions in Dying and Bereavement includes key considerations for a particular stage of the dying or bereavement process. Interventions are suggested based on assessment questions to be asked of patient or family at each stage. Advice is given about how to address the subjects’ answers to each question, and special issues that emerge at particular times (e.g., patient and family dissonance in adjusting to recurrence of an illness) are discussed in depth. The authors then describe some of their own experiences in each area of concern by explaining what they do and how they go about their work at each stage. Team issues are also addressed, and exercises for reflective activities designed primarily for hospice workers are included at the end of each chapter.

Due to the fact that there is such an attempt to be thorough and detailed in this volume, much of it will appeal primarily to hospice professionals. The textbook quality is humanized, however, by personal vignettes from hospice team members, poems, quotations, cartoons, photographs, and other relevant inserts. These are carefully presented in alternative typefaces, sidebars, and in places appropriate for effectively drawing the reader’s attention. Regretfully, there is no information included to give readers insight into patients’ near-death awareness as discussed in books such as Final Gifts (Callanan & Kelley, 1992). However, this is a minor issue. Transitions in Dying and Bereavement is an impressive contribution to literature on palliative care and should be on the bookshelf of every hospice professional. As Ira Byock describes this book on its back jacket, “It is a wise and generous resource for clinicians in practice, students, and people who are themselves dealing with life-limiting illness and want to delve deep within the science and art of psychosocial and spiritual care.” If we as a society wish to assist people in reducing death denial and anxiety so they can live more effective, productive, and less fear-filled lives, then providing an educational, supportive, caring environment for dying persons and their families can be of great social benefit. Victoria Hospice Society is to be commended for explaining ways to do this and for setting a high standard for palliative care.

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References