

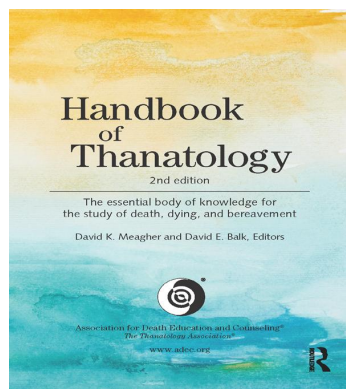
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## **Handbook of Thanatology**

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

David K. Meagher, David E. Balk

### **Historical and Contemporary Perspectives on Dying**

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## Chapter 3

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# Historical and Contemporary Perspectives on Dying

*Kenneth J. Doka*

### Early Efforts

While many people associate the historical roots of the study of dying with Kübler-Ross' epochal book *On Death and Dying* (1969), in fact, the roots of the field are earlier. In this section, I will explore some of the early and contemporary contributions to the study of the dying process. This chapter begins with a brief history of some of the early formative work, reviews the development of the concept of anticipatory grief, describes more contemporary efforts to develop task models of dying, and discusses theorists who have viewed dying as a developmental and transformative experience. This chapter in no way presents a comprehensive review of all the work that exists on the field. Rather, it represents the author's perspective of influential work that has contributed to the care of the dying. Persons who wish a more all-inclusive view may wish to consult varied social histories of the field (Pine, 1977; 1986; Corr, Doka, and Kastenbaum, 1999).

Perhaps one of the earliest efforts to understand some of the psychosocial processes of dying was Lindemann's (1944) study of grief reactions that introduced the concept of *anticipatory grief*—a topic that will be explored later in this section. Feifel's *The Meaning of Death* (1959) was one of the first publications and early efforts in the field. Though the book had a broad focus, some of the articles did address the dying process. In that same year, Cicely Saunders, who founded St. Christopher's Hospice, published a series of articles focusing on nursing and the dying (Saunders, 1959). In 1962, Weisman and Hackett published a study on dying patients and the predilection to death.

Glaser and Strauss also published, in that era, two books that would contribute some enduring concepts to the study of the dying process. In *Awareness of Dying* (1965), Glaser and Strauss studied what dying people knew or suspected about their impending deaths. It is important to remember that in that period, general practice was not to discuss death with individuals who were dying. Nonetheless, Glaser and Strauss documented that dying individuals experienced four different awareness contexts. In *closed awareness*, the

dying person had no inkling of his or her impending death. As Glaser and Strauss noted, this context was unstable and unlikely to last long as dying individuals began to respond to both external and internal cues. In *suspected awareness*, dying individuals expected their impending death—often trying to test their suspicions with medical staff or family. A third context—*mutual pretense*—was the most common. Here patients and family were aware of the impending death, but to protect the other each person pretended that the patient would recover. A last context—*open awareness*—occurred when both patients and family were aware of and could discuss the possibility of death. Glaser and Strauss' (1965) work played a significant role in questioning the veil of silence that had surrounded the dying process.

Their second work, *Time for Dying* (Glaser and Strauss, 1968), focused on the temporal organization of death within the hospital. They noted that most deaths followed certain expected trajectories. "Badly timed" deaths, where the death did not follow an expected trajectory, often created great difficulty for staff.

Sudnow's *Passing On: The Social Organization of Dying* (1967) was an ethnographic account of dying in two hospitals. While Sudnow's work was wide-reaching and touched on numerous themes, one of his most enduring contributions was the introduction of the concept of *social death*. Social death referred to his observed phenomenon that family and staff often treated many comatose patients, though technically living, as if they were dead.

### **Hospice: A Way to Care for the Dying**

In this early period, Saunders founded St. Christopher's Hospice, often credited as the first hospice, in the London area. Saunders emphasized that dying was not simply a biomedical or physical event but also had psychosocial, familial, and spiritual implications. Care of the dying needed to be holistic and centered on the ill person and his or her family as the unit of care. St. Christopher's tried to create a homelike atmosphere that sought a holistic, family-centered way to allow dying persons to live life as fully as possible, free from debilitating pain and incapacitating symptoms. Both the hospice philosophy and the growth of hospice did much to improve the treatment of dying persons and to encourage the study of the dying process.

The hospice movement's remarkable history is well-noted in other sources (see for example, Stoddard, 1978). It is, perhaps, one of the most successful grassroots movements in the last quarter of the 20th century. The holistic philosophy of hospice has permeated much of medicine now—at least in terms of a recognition that a patient's quality of life means meeting not only physical needs but psychological, social, and spiritual needs as well. Moreover, the success of hospice has led others to seriously question how well the medical system generally meets the needs of those who are dying as a result of multiple serious chronic illnesses (Myers & Lynn, 2001).

St. Christopher's became a beacon both of research and practice generating seeds that would grow throughout the world. Literally many of the pioneers who would influence the development of hospice and palliative care visited or trained there.

In the United States the success of St. Christopher's resulted in the development of Hospice Inc. outside of New Haven, CT, in 1974. Branford also had a small home care unit. But it was William Lamers, a founder of a hospice in Marin County, CA, that viewed home care as both the heart and future of hospice. To Lamers, the idea of a homelike environment could best be offered within the patient's actual home. Lamers offered a model that freed interested individuals from fundraising for new facilities. This home care model of hospice quickly spread throughout the United States sponsored by a range of groups from churches and interfaith groups to junior leagues. Hospice then took a very different cast in the United States compared to England in that, in the United States, hospices primarily offered home care and heavily stressed psychosocial care and the use of volunteers (Connor, 1998).

Not everyone learned the same lesson at St. Christopher's. St. Christopher's impressed Balfour Mount, a Canadian physician. However, Mount was convinced that the lessons of St. Christopher's need not necessarily lead to a new form of care but could be applied even in the high-technology environment on the modern hospital. When he returned to the Royal Victoria Hospital in Montreal, Canada he pioneered the development of a hospital-based palliative care model.

To Saunders and Kastenbaum (1999), the growth of hospice was a reaction to a number of trends. First, technology-driven medicine focused on cure, seemingly abandoning those who were no longer responsive to treatment. Second, hospice resonated with two other themes of the era—consumerism and return to nature. Both trends converged on the idea that individuals could create alternative, more natural organizations, where persons could take control of their lives—and their deaths.

The hospice movement, both directly and indirectly, also accelerated interest in complementary and alternative therapies. Complementary therapies may be defined as those treatments, such as imagery or diet, that are employed *in addition to* conventional medical approaches, while alternative approaches are those that are used *instead of* conventional medical treatment (Doka, 2009). The holistic nature of hospice care has led to a range of additional treatment modalities including bodywork, acupuncture, and expressive therapies to provide palliation (Kalauokalani, 2006). The same consumerist orientation that supported hospice also fueled interests in alternative approaches.

### **Kübler-Ross and *On Death and Dying***

Few of these efforts, at least in the very beginning, captured as much public attention as did the publication of Kübler-Ross' *On Death and Dying*. The book appeared at the right moment. Kübler-Ross was a charismatic woman who spoke of a "natural death" at a time when there was an increased aversion to technological and personal care (Klass & Hutton, 1985). Her message found a ready audience.

Kübler-Ross posited that dying persons went through a series of five (now famous) stages—denial, anger, bargaining, depression, and acceptance. Through her case vignettes, she made a powerful plea for the humanistic care of the dying patient. In an

excellent evaluation of Kübler-Ross' contributions, Corr (1993) suggests that this call for humanistic care and her affirming message to talk to dying persons, along with the heuristic value of the work, are the enduring legacies of the book.

The stages, though still popular in lay literature, are far more problematic. Evaluations of her theory of stages (see, for example, Doka, 1993) note many problems. Some are methodological in nature. Kübler-Ross never really documented her material. It is unclear how her data were collected or how many patients experienced what reactions. Nor has research supported the concept of stages (e.g., Schulz & Aderman, 1974). There are other problems as well. While Kübler-Ross insisted that the stage theory was not to be understood literally or linearly, the book clearly offers an impression of linear stages. As such, individual differences and the diverse ways that persons cope are often ignored. In addition, it is unclear whether the stages represent a description of how persons cope with dying or a prescriptive approach that stresses that dying individuals ought to be assisted to move through the five stages and eventually embrace acceptance.

Weisman's (1972) work on denial suggests another difficulty—denial and acceptance are far more complicated than Kübler-Ross perceived. In his work, Weisman described orders of denial emphasizing that patients might deny symptoms, diagnosis, or impending death. Weisman notes that denial is not always negative. It allows patients to participate in therapy and sustain hope. Weisman introduces a very significant concept of *middle knowledge*—meaning that patients drift in and out of denial; sometimes affirming, other times denying the closeness of death. To Weisman the important question was not “Does the patient accept or deny death?” but rather “When, with whom, and under what circumstances does the patient discuss the possibility of death?”

In summary then, the 1960s and 1970s were a formative time for the study of dying. In this period many of the classic works and key concepts were developed. It also was a period when hospice continued to develop and begin to expand.

### **The Evolution of the Concept *Anticipatory Grief***

In the closing section of his study on acute grief, Lindemann (1944) noted that grief reactions could be in anticipation of loss. Fulton and associates (Fulton & Fulton, 1971; Fulton & Gottesman, 1980) attempted to develop this concept. Fulton's concern was that the term was easily misused. Fulton wrote at a time when many clinicians attempted to “encourage” family members to experience anticipatory grief under the assumption that the acknowledgement and processing of the grief prior to the loss would mitigate grief experienced after the death. He later described this approach as a “hydrostatic” perspective of grief—indicating a zero-sum notion of grief, that is, that there is just so much grief or tears that can be expended. Therefore whatever is experienced earlier on in the illness will not need to be encountered later (Fulton, 1987). Moreover, foreknowledge or forewarning of death does not seem necessarily to imply that anticipatory grief occurs. It is little wonder that research found little evidence that the anticipation of loss positively influenced later grief outcomes (see Rando, 2000, for an extensive review). Fulton

has since reevaluated the concept, stating “I have serious reservations regarding the heuristic value—either theoretical or practical—of the concepts ‘anticipatory grief’ and ‘anticipatory mourning’” (Fulton, 2003, p. 348).

Rando (2000a), though, has offered an extensive revision of the concept. Rando acknowledges that the term *anticipatory grief* is a misnomer. Yet, she still finds it useful. Rando redefines *anticipatory grief* referring to the phenomena as *anticipatory mourning*. This is a critical distinction. Anticipatory grief refers to a reaction while anticipatory mourning is a far more inclusive concept referring not only to reactions experienced but also the intrapsychic processes that one uses to adapt to and cope with life-limiting illness. Rando also redefines the concept as referring not only to the grief generated by the possibility of future loss but primarily as a reaction to the losses currently experienced in the course of the illness. The patient is not the only person to incur these losses. Family members and even professional caregivers may experience these losses as the patient continues to decline. Rando’s reformulation then frees the concept from much of the earlier misconceptions that proved problematic.

### **Task and Phase Models of Coping With Life-Threatening Illness and Dying**

Worden’s publication of *Grief Counseling and Grief Therapy* (1982) represented a paradigm shift in the way we understand mourning—one that would contribute to the study of dying as well. While prior models offered a more linear stage or phase theory to explain the mourning process, Worden conceptualized mourning as a series of four tasks. As Corr (1992) noted, the use of tasks offered certain advantages. Implicit in the concept of tasks was an inherent assumption of individuality and autonomy not often seen in stage models. Bereaved individuals might find it easier to cope with some tasks than with others. They would complete tasks in their own unique ways. And grieving persons would complete these tasks on their own timetable or even choose not to address certain tasks. Also unlike stage theories, there was no assumption of linearity. Moreover a task model had clear clinical implications. A grief counselor could assist clients in understanding what tasks they were struggling with and facilitate these grieving clients as they sought to work on these difficult tasks.

Both Corr (1992) and Doka (1993, 1995) applied the concept of tasks to the dying process. To Corr, coping with dying involved four major tasks that correspond to the dimensions of human life—physical, psychological, social, and spiritual. The physical task was to satisfy bodily needs and to minimize physical distress in ways that are consistent with other values. Corr defined the psychological task as to maximize psychological security, autonomy, and richness. The social task was to sustain and enhance those interpersonal attachments that are significant to the person concerned and to sustain selected interactions with social groups within society or with society itself. Corr’s spiritual task was to address issues of meaningfulness, connectedness, and transcendence and, in doing so, to foster hope.

Building on the work of both Pattison (1978) and Weisman (1980), Doka (1993, 1995) suggested that a life-threatening illness can be understood as a series of phases, noting that not all phases would appear in any given illness. The *prediagnostic phase* concerns itself with the process of health seeking. It refers to the time prior to the diagnosis. One of the most common, but not the only context, would be the time between when an individual notices a symptom and seeks medical assistance. The *acute phase* refers to the crisis period surrounding the diagnosis of life-threatening illness. The *chronic phase* refers to that period when the individual struggles with the disease and treatment. Many individuals may recover from the illness. However, Doka reminds that in the *recovery phase*, individuals do not simply go back to the life experienced before illness. They still have to adapt to the aftereffects, residues, and fears and anxieties aroused by the illness. The *terminal phase* revolves around adapting to the inevitability of impending death as treatment becomes palliative.

At each phase, individuals have to adapt to a series of tasks. These tasks derive from four general or global tasks—to respond to the physical facts of disease, to take steps to cope with the reality of the disease, to preserve self-concept and relationships with others in the face of the disease, and to deal with affective and existential/spiritual issues created or reactivated by the disease.

Though these models seem to have interesting implications for understanding the ways that individuals cope with dying and life-threatening illness, they have not been widely applied. Yet, they still represent a possible direction as we strive to develop new approaches and models of the dying process.

### **Future Trends**

Dying continues to evolve. In recent years the four leading causes of death in the United States and many industrialized countries include cardiovascular diseases, cancer, cerebrovascular diseases, and respiratory diseases. Moreover as the population ages, it is not unusual that many patients will have multiple chronic conditions at end of life. This aspect of aging has made medical management of the dying process more complicated both ethically and medically. Ethically, it raises the question of whether some chronic conditions should be treated when the goal of care has become palliative. Medically it means that multiple conditions are being simultaneously treated, making both treatments complex, and the dying trajectory less predictable. This emerging medical reality has led to an interest in concurrent care—or medical treatment where palliative care is offered concurrently with life-extending treatment.

### **The Possibilities in Dying**

In addition to coping with dying, there has been some work on possibilities for continued growth and development throughout the dying process. Kübler-Ross (1975), in her edited book, *Death: The Final Stage of Growth*, suggested that accepting the finiteness of life allows us to more fully live life—discarding the external roles and petty concerns that are essentially meaningless. Dying persons are our teachers, she asserts, since accepting the

limited time left in their lives they can focus on what is truly important and meaningful.

Byock (1997) in his book *Dying Well: The Prospect for Growth at the End-of-Life* suggests that once a dying patient is freed from pain, that person retains the human potential to grow and the possibility to use his or her remaining time to express love, finish significant and meaningful tasks, and reconcile with others.

The key caution is to remember that these are possibilities—possibilities to be embraced by the dying person. They become a danger when others, whether family members or health professionals, see it as their goal to induce the dying person to achieve such possibilities. Shneidman (1992) offers a fitting caution that no one has to die in a state of “psychoanalytical grace.”

### **Conclusion**

While the study of grief abounds with exciting ideas and the hospice movement has expanded exponentially, the study of the dying process has been relatively neglected. It can be hoped that the next decade will be one of increased attention to and development of new ways to conceptualize the ways that individuals experience dying and evidence-based interventive strategies to assist dying persons, their families, and their caregivers.



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