

# Current Comments

## Death Be Not Proud— Meeting the Needs of the Dying through Thanatology

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Death and dying are not particularly pleasant or popular subjects. Oh yes, people apparently want to hear about them in the news. They are indeed fascinated by this subject when it is portrayed in films, disaster reports, and the like. But in the final analysis, death is a subject most of us prefer to avoid. There are enough reminders of it every day—in reports of wars, pestilence, and accidents and in the deaths of friends and relatives, especially as one grows older.

In recent years, I've experienced the loss of several friends. Nobelist Harold Urey lived to the age of 87 and left the world greatly enriched.<sup>1</sup> I recently attended a beautiful memorial meeting for Harold at Scripps Institution of Oceanography in La Jolla, California. An old friend and colleague, Fred Tate of *Chemical Abstracts (CA)*, died suddenly.<sup>2</sup> We met when he worked at Wyeth Labs in Philadelphia. I often wonder what would have transpired had he accepted my offer to come to ISI®. But he helped change *CA* into a leading center for information retrieval.

Then I heard that my cousin, Harry Bauer, in far away Cape Town, South Africa, died. All such events are reminders that life is finite. Almost 400 years ago, John Donne wrote: "Death be not proud, though some have called thee/Mighty and dreadful, for thou art not so.... One short sleep past, we wake eternally/And death shall be no more; Death, thou shalt die."<sup>3</sup> (p. 192) These

words still apply to man's condition no matter how firmly we do, or do not, believe in the hereafter or the finality of death.

As if dealing with our own eventual nonexistence were not enough of a burden to carry all our lives, some of us must also deal with the unexpected deaths of those we love. Children represent for many a form of immortality, and so the loss of a child is a particularly heavy blow. We pour so much love into our children and fear for them at every turn, especially when they are infants. And then suddenly death may come. The effect varies from person to person and is often hard to describe adequately. Last year I lost my daughter, Thea, and it is a formidable step for me to even say that here. But her life and death take on some added meaning if in some way they make life's problems easier for others to endure. And that is, in part, why I think the subject matter of this essay is so important.

Unexpectedly, when you go through a death experience you are surprised to learn how many of your friends and associates have been there before. But in spite of this experience, I myself have no prescription for coping with death. Though the death of someone we care about is painful, most of us ultimately find the strength to go on because life is a wondrous and beautiful experience.

It is somewhat ironic that back in 1967 when I first wrote about *ASCA*® (*Automatic Subject Citation Alert*),<sup>4</sup> I

used death and dying as an example of a topic on which it was difficult to retrieve information. As I explain later, citation searching was about the only way you could gather information on the subject. That has changed dramatically since the emergence of the field of thanatology.

In the early 1970s, while speaking at a Foundation of Thanatology conference in New York,<sup>5</sup> I also noted that except for occasional articles appearing in scattered journals, there was no periodical a thanatologist could turn to for specific information on death and dying. Then, as now, thanatology was a multidisciplinary field focusing on the psychological, social, and medical needs of the dying patient. In response to a 1977 *Special Libraries*<sup>6</sup> article lamenting the lack of interdisciplinary coverage of death and dying, and abortion, by secondary information services, Tony Cawkell, ISI's former vice president of research, did a *Permuterm*<sup>®</sup> subject search on the word "death."<sup>7</sup> He found the multidisciplinary nature of this subject was well-represented in the articles retrieved through the *Social Sciences Citation Index*<sup>®</sup> (*SSCI*<sup>™</sup>).

The 1970s was a period of growth for this discipline. As it expanded, the term thanatology—taken from Thanatos, the Greek god of death—took on added meaning. Thanatology now includes such topics as bereavement, anticipatory grief, the social and psychological effects of death on families, and the anticipatory phases of life-threatening illnesses such as heart and cardiovascular disease. This growing field, following the traditional patterns of publishing,<sup>8,9</sup> has spawned several publications dealing exclusively with death and dying.

People have always died, or gone through the "process of dying." So why this recent interest in thanatology? There are a number of reasons, not the least of which is the success of medical science in eliminating many of the diseases that caused death among infants

and children. People are living longer, and succumbing more often to such degenerative illnesses as cancer and heart disease. Biomedical advances have made it possible for people to live much longer with these illnesses that earlier might have caused a rapid death. The process of dying is now a clearly identifiable phase of life. This can be a painful period for the sick person and his or her family. On a more positive note, however, this period can provide the individual with an opportunity to put legal, financial, and emotional affairs in order and to say goodbye to family and friends.

In previous generations, people died in their homes, surrounded by people and objects that held meaning for them. Now, most people die in hospitals and nursing homes, away from their familiar environment. This change has deprived the dying individual of many comforts, and has turned death into an isolated, "unnatural" event that most people rarely encounter. So when we must face our own death or the death of someone very close, we have no background of experience or knowledge on which to rely. The emotional coping mechanisms our grandparents developed as a result of their more frequent and natural encounters with death are not available to us.

Even people who have frequent contact with death may find it difficult to deal with their own death or that of others. Physicians, nurses, and other health care providers—uncomfortable in the presence of death—may often avoid dying patients or otherwise let them know they have given up. This kind of attitude is partially a reflection of the health care provider's own anxieties about death, and his or her defense mechanism for coping with frequent death and impersonal hospital procedures.

This avoidance of dying patients can also be attributed to the medical community's perception of itself as a "cur-

ing" rather than "caring" force. Writing of his personal encounter with cancer, Ralph Redding, Jackson Memorial Hospital, Miami, Florida, explains: "In medical training, death has become the enemy; and in losing a patient, doctors often feel that they have failed medically, or worse still, made some terrible mistake."<sup>10</sup>

Redding adds that medical schools emphasize "fact oriented knowledge" needed for diagnosing and treating patients. Doctors are not usually educated to meet the emotional needs of their patients. They are unable to discuss a patient's impending death and, often, under the guise of protecting the patient, don't let that patient know he or she is terminally ill.

This estrangement from death has led a number of researchers to investigate the emotional processes of the dying person and the people who share this phase of his or her life. It has also instigated research into bereavement and grief. In an excellent review of the historical development of death education, Vanderlyn R. Pine, State University of New York at New Paltz, points out that interest in bereavement preceded interest in the dying process.<sup>11</sup> Another good review of death education is presented by Dan Leviton, University of Maryland, in *New Meanings of Death*.<sup>12</sup> Although studies and case reports on bereavement and funeral practices were published sporadically in the 1920s and 1930s, Pine credits psychiatrist Erich Lindemann, Harvard University, with providing the foundations for many of today's theories on bereavement, grief, and mourning. In the 1940s Lindemann found that more than 80 percent of patients suffering from ulcerative colitis had a poorly managed grief experience in the six months preceding the onset of symptoms.<sup>13</sup> He and his colleagues also noticed that patients in acute grief as a result of a major fire healed measurably slower than those who had experienced no grief.<sup>14</sup>

Research on the actual process of dying began a bit later, in the 1950s. In work that has had a profound impact on future psychiatric treatments of death, Kurt R. Eissler<sup>15</sup> wrote about the psychiatric problems of the dying patient. A number of thanatologists trace the origins of the current study of the emotional aspects of dying to a 1956 American Psychological Association meeting session on the topic of death. This session was organized by Herman Feifel, VA Outpatient Clinic, Los Angeles, California, who edited one of the earliest and most important scholarly books in the field.<sup>16</sup> It was the basis of the death and dying profile I created when I first described ASCA to social scientists.<sup>4</sup>

Much thanatology research is still directed toward determining and meeting the needs of a dying person, and helping that person's family through what psychiatrist Elisabeth Kübler-Ross calls this "final stage of growth" and bereavement.<sup>17</sup> A number of very strong principles about patient's rights emerge from a review of the death and dying literature. These are cogently summarized by Daniel R. Longo, National Naval Hospital, Bethesda, Maryland, and Kurt Darr, George Washington University. They write:

The terminally ill: (1) must be given the possibility of achieving acceptance of death with dignity; (2) have rights, including the right to be involved in decision-making processes; (3) should be allowed to die as they have lived—family and friends especially have the role as caretakers; (4) should be made as free from pain as possible; and (5) should be regarded as persons who are going through a natural, rather than an unnatural process.<sup>18</sup>

One of the initial findings of studies on dying patients was that many, without being told directly, are aware of their impending death and wish to discuss it. In a seminal study of patients dying in a London hospital, J.M. Hinton,

Middlesex Hospital, reported "...at least three-quarters of the patients... became aware they were probably dying..." He concluded, "The problem (of determining whether a patient should be told he or she is dying)... resolves itself into discovering what the patient knows, and how much more he really wants to know, information that can be gathered with no distress in a quiet, unhurried conversation. In my opinion, if the awareness of the patient is so great that he has formulated the question, an honest answer which does not destroy all hope will not add to his distress."<sup>19</sup>

In an effort to understand the experiences of a dying person, and help him through this final phase of life, a number of investigators have described "stages" or "phases" dying patients go through after learning of their terminal illness. These stage theories have been reported in the academic literature,<sup>20</sup> and were brought to the public by Kübler-Ross in her 1969 book, *On Death and Dying*.<sup>21</sup> Briefly, the five stages identified by Kübler-Ross are: (1) denial and isolation ("No, not me, it cannot be true."); (2) anger ("Why me?"); (3) bargaining (entering into some sort of an agreement which may postpone the inevitable happening); (4) depression; and (5) acceptance. Of course, dying is a highly individualized process and dying people do not rigidly follow this or any other model.

Tillman Rodabough, Baylor University, in a recent review of three such models, suggests that individuals vacillate between acceptance and denial even when they do follow a given behavioral model. Describing his "Interpersonal Reactions Model," Rodabough proposes that a dying person—taking cues from the people around him or her—behaves and expresses the emotions expected by the observer.<sup>20</sup>

Thanatological investigations have led to an awareness that dying is a

unique phase of life, and that dying people have needs that are not being fully met in current social institutions. Of particular concern is the terminally ill patient's need for relief from the pain that often accompanies the final stages of illnesses such as cancer, and heart and neurological disease. Many health care providers have found that the impersonal atmosphere of most hospitals, and feelings of isolation and loneliness from being in unfamiliar surroundings, can exacerbate this pain. Unfortunately, the need for medication and other medical intervention, and pressures on the family, can make it difficult for a terminally ill person to die at home.

In England and, more recently, the US, the *hospice* concept has been revived to meet the dying patient's need for a peaceful environment where both medical and emotional support can be provided. Robert Butler, director of the National Institute on Aging in the US, describes the hospice as "a place dedicated to providing comfort, support and dignity for those who are dying."<sup>22</sup> Hospices are the modern versions of hostleries for pilgrims operated in the Middle Ages by religious centers seeking to fulfill the Biblical directive: "Inasmuch as ye have done it unto one of the least of these My brethren, ye have done it unto Me."<sup>23</sup> Like their earlier counterparts, many hospice workers are dedicated to serving God by caring for the sick and dying on their "last journey."

Although a few of the almost 200 hospices listed in the National Hospice Organization's *Member Locator Directory*<sup>24</sup> are freestanding, residential buildings, a different hospice concept is emerging in the US. As described by Butler, hospice "...must be viewed as a body of knowledge, an array of practices, and a set of concepts and attitudes that emphasize comfort, support and dignity for the dying and their survivors."<sup>25</sup> This concept has caught

on in the US and hospices in this country range from the large unit in Branford (New Haven), Connecticut, which serves only terminal patients to the "scatterbed" type of hospice at St. Luke's Hospital in New York, where terminally ill people are interspersed with other patients, but attended by a special staff. Many hospices are actually home care programs in which a staff serves dying patients, as needed, in their homes.

Since hospices are dedicated to caring for the dying, rather than curing disease, hospice workers' attitudes toward pain management differ from those of individuals caring for people who are likely to recover from illness, and therefore, must not be allowed to become addicted to painkillers. Butler and the majority of people involved in the "hospice movement" believe prescription practices should allow terminal patients to feel as little pain as possible. This usually means administering pain relief before any pain is felt. Butler writes:

In this way, it is possible to erase both the memory and fear of pain, thus enabling the patient to review his or her life in peace and come to terms with approaching death. This approach differs from the currently fashionable... 'as necessary' regimen, whereby the patient is allowed to develop pain, must then wait while it worsens (complaining is discouraged), and finally calls for a nurse, who administers the drug at her or his earliest convenience. More time is needed for the medication to take effect, and the dying person's last hours are filled with anxiety, anger and cyclical pain.<sup>22</sup>

Both Butler<sup>25</sup> and Cicely Saunders,<sup>26</sup> medical director of St. Christopher's Hospice, England, stress that pain relief, rather than addiction, should be the concern of doctors administering to the terminally ill. The British government, apparently, agrees. An oral medication which includes diamorphine

(heroin) and cocaine is currently being administered to dying patients in the UK. What Butler describes as "excellent pain control"<sup>25</sup> has been achieved with this mixture. As a result, the National Cancer Institute in the US has developed stable dosage forms of heroin which have been used in research protocols at Memorial Sloan-Kettering Cancer Center and Georgetown University. This mixture, known as Brompton's cocktail or mix, the pain cocktail, or the hospice mix, is more commonly administered with morphine or methadone,<sup>27</sup> rather than heroin, in the US. A good review of clinical use of this mixture is presented in a 1974 article by R.G. Twycross, St. Christopher's Hospice.<sup>28</sup> Saunders stresses that, properly administered, these drugs need not lead to drug dependence or tolerance.<sup>26</sup>

One of the contributions of those concerned with the terminally ill has been the attention they have focused on better means of chemical, surgical, and psychological pain control. The National Institute on Aging (NIA) is supporting research on the pharmacology of aging and is a participant in the joint NIA-Alcohol, Drug Abuse and Mental Health Administration, Interagency Committee on New Therapies for Pain and Discomfort.<sup>25</sup>

The NIA is also funding research on the reaction of the patient's survivors both before and after his death. Researchers are looking at the stages the family goes through in accepting the death of a member, the roles played by religion and ritual in helping people come to terms with death, the incidence of morbidity and mortality among grieving people, and other physical, social, and psychological effects of bereavement.

Much of the bereavement research done in the past 30 years has built on the findings of Lindemann and his colleagues, whom I mentioned earlier. Their reports on the adverse physical ef-

fects of bereavement have been confirmed by a number of investigators. For example, A. Schmale, Rochester University, found that 98 percent of the patients admitted to Strong Memorial Hospital in Rochester, New York, during a 23-day period experienced loss (of an object or person), accompanied by feelings of helplessness and hopelessness, prior to the onset of illness.<sup>29</sup> Similarly, a study reported in England in 1963<sup>30</sup> and followed up in 1969<sup>31</sup> found that widowers' mortality rate was "40% above the expected rate for married men the same age." More recently, in a review of epidemiological studies conducted since 1959, Adrian Ostfeld and Selby Jacobs, Yale University, concluded there may be an excess mortality of several thousand Americans annually as a result of significant personal loss.<sup>32</sup>

Bereaved individuals are evidently an "at risk" population. It is therefore not surprising that psychologists and psychiatrists, among others, have investigated the grieving process and the consequences of being unable to healthfully "work through" this grief.

A number of different "stage" models of the grieving process have been advanced by researchers and therapists.<sup>33-35</sup> All generally follow the course described by Lily Pincus, Tavistock Institute of Human Relations, London, in her book *Death and the Family*.<sup>35</sup> According to Pincus, most people initially react with shock, disbelief, and denial. Often family and friends try to help by sedating the mourner and advising him or her to keep busy, thus avoiding facing the death. Such advice, psychologists, ministers, and family therapists agree, is wrong because it sets the stage for further denial of loss and pain. If delayed, the pain, anger, and guilt repressed at this point will surface later in some unexpected and unhealthy fashion. The longer grief is denied, the more virulent its expression.

Roy and Jane Nichols, funeral directors, advise their colleagues not to shield mourners from pain and to permit them as much involvement in the funeral process as possible. They write: "We cannot take the pain away. Whereas the grieved person may want withdrawal from reality (who wouldn't), there is frequently a strong difference between what people want and what they need. We all must be aware of the extreme dangers of delayed, avoided grief and must develop the skills, the openness, the accepting attitude which will allow the grieved person to accept the death he has sustained."<sup>36</sup> According to Leviton, funeral directors, because of their experience with the bereaved, have come to play an important role in the resolution of grief.<sup>37</sup> But this can largely depend upon how well the family is known to the funeral director. Platitudes and clichés are not particularly welcome at such crises.

The next stage of grief is what Pincus calls the "controlled phase." This can be the most painful period for the mourner. The shock and numbness of the earlier phase have worn off. The little things that make up a relationship make themselves known at this point, and the bereaved feels lost and abandoned. People often, consciously and unconsciously, search for the lost person by looking for his or her face in a crowd, or by having dreams and hallucinations about the deceased. People can be restless and tense during this time and need the support and safety of family and friends. During this stage, the physical and psychological manifestations of grief can be very real and acute. Dennis M. Reilly, SNG Counseling Center, Wadsworth, New York, cites such symptoms as panic attacks and hysteria, nausea, dizziness and digestive upsets, insomnia, impotence, and identification with the deceased and his symptoms.<sup>38</sup>

The final stage is adaptation, or resolution of the grief. At this point, the

mourner can withdraw the emotional attachment to the loved person and can think, talk, and feel about him or her without the intense pain of the earlier stage. Pincus describes this as "internalizing" the deceased. Edgar N. Jackson, a consultant and author, compares the emotion of grief with physical amputation and its resolution with adjustment to missing a limb. He describes grief as "removal of part of the feeling structure of life..." and offers this explanation of the bereavement process: "The root emotion of grief grows from this identification with another so completely that a part of our own being lives and feels with that person.... Mourning is the process by which the emotional capital invested in the love object is withdrawn so that it can be reinvested where it can do good in life."<sup>39</sup> Emotional bondage to the deceased must be broken before grief can be resolved.

Although there are no hard and fast rules, the period of intense grief is generally passed by the fifth or sixth month while the end point of grieving seems to arrive between one and two years after the death. A person who grieves well beyond this period clearly needs professional psychiatric or psychological help. Doctors Jacobs and Ostfeld advise physicians to be familiar with the grieving process so that they can listen to and validate their patients' emotional responses to loss. When a bereaved individual is not being given the opportunity to grieve, they recommend the physician meet with the family to validate the survivor's experience. If a patient cannot resolve his or her grief, if he or she feels out of control, or delays or prolongs the grieving process, they suggest the mourner receive therapeutic help.<sup>40</sup>

In reviewing the thanatology literature, one cannot help but notice that the majority of articles were written by scholars and educators from the US. A great deal of work is also being done in

the UK, Canada, and Australia. Leviton attributes the large number of articles written by people in the US to our pervasive need to control our lives. He points out that the US also leads the world in research and education on sex, another generally taboo subject.<sup>37</sup>

A number of clinical, as well as academic and thanatological, journals now publish articles on death and dying. Usually these articles describe counseling and other special programs for dying patients, and educational or counseling programs to help physicians, emergency room personnel, nurses, and other health care providers cope with the death of patients. Although these people have frequent exposure to death, they have not until recently been taught how to help a dying patient come to terms with his or her death. The importance, and popularity, of courses on death and dying is reflected by the fact that a journal was started three years ago to deal with the specific subject of death education. It is, very appropriately, entitled *Death Education*. Published in association with the Center for Gerontological Study and Programs at the University of Florida, this journal carries articles covering the spectrum of thanatological disciplines. For more information on this journal, contact the Hemisphere Publishing Corp., 1025 Vermont Avenue, NW, Washington, DC 20005.

Another journal, *OMEGA: Journal of Death and Dying*, carries research reports on various aspects of thanatology. Started in 1966 as a newsletter for interested scholars, this journal has become the official publication of the Forum for Death Education and Counseling. The Forum is an organization of researchers and educators concerned with promoting and upgrading the quality of death education and dying and bereavement counseling. They offer workshops on death education and counseling in several cities in the US and can be contacted by writing Forum

for Death Education and Counseling, Inc., P.O. Box 1226, Arlington, Virginia 22210. *OMEGA* is published by the Baywood Publishing Company, Inc., 120 Marine Street, P.O. Box D, Farmingdale, New York 11735.

*Advances in Thanatology* (formerly *The Journal of Thanatology*) is the official publication of the Foundation of Thanatology. This educational and scientific organization has sponsored more than 30 symposia on issues related to death and dying. These symposia have generated a number of research reports, monographs, and over 40 books. The Foundation also publishes the *Archives of the Foundation of Thanatology*, a quarterly journal of abstracts and some full papers from symposia, and *Thanatology Abstracts*, which summarizes published articles. For information on all three publications write the Foundation at P.O. Box 1191, Brooklyn, New York 11202. The Foundation is closely associated with the College of Physicians and Surgeons at Columbia University and can be reached through Austin H. Kutscher, President, 630 West 168th Street, New York, New York 10032.

*Essence*, a Canadian thanatological journal, can be obtained by writing the editor, Stephen Fleming, at York University, Atkinson College, 4700 Keele Street, Downsview, Ontario M3J 2R7, Canada. The official publication of the American Association of Suicidology, *Suicide and Life-Threatening Behavior*, Human Sciences Press, 72 Fifth Avenue, New York, New York 10011, also carries articles of interest to thanatologists. *OMEGA*, *Essence*, *Suicide and Life-Threatening Behavior*, and *Death Education* are covered by *Current Contents®/Social & Behavioral Sciences* and the *SSCI*.

Individuals interested in obtaining specialized bibliographies on thanatological subjects or the *Thanatology Librarian*, a newsletter which reviews books on death and dying, can write

Roberta Halporn at Highly Specialized Promotions, 391 Atlantic Avenue, Brooklyn, New York 11217.

Thanatology is a firmly entrenched, multidisciplinary field. Beyond its direct contributions to the needs of dying and bereaved individuals, it promises to enrich the knowledge of a number of different disciplines. Psychologists and social workers are helping physicians and nurses understand the role played by the patient's environment, and mental and emotional states, in pain control. Philosophers and clergy are helping psychologists, social workers, and funeral directors understand and use rituals that aid in acceptance of death and the resolution of grief. Although there now are many expressly thanatological journals, literature of interest to thanatologists can be found in a wide variety of journals. Even the organizations that fund thanatological research—the National Institutes on Aging and Mental Health and the National Cancer Institute—represent a variety of disciplines.

Unfortunately, every advance in technology has increased the chances for accidental death—whether in an airplane, or a car, or by some other means. Since the probability of nonnatural death is increased, as with every other type of medical emergency, we need to know how to cope with it. For this reason, the field of thanatology is clearly a discipline that will grow until our education and culture make knowledge of the processes of death, dying, and bereavement commonplace. Even when death is no longer an implicitly taboo topic, there will still be a need for professional knowledge of how to deal with dying and bereavement. Death education and research will continue to help thousands of people cope with these painful phases of life.

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