American Handbook of Psychiatry

HELP IN THE DYING PROCESS

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Death has long been a taboo topic in American culture. But in a manner similar to the broaching of sexuality as a subject for investigation at the turn of the twentieth century, the decade of the 1960's has witnessed the broaching of death and dying. Research into this taboo area has presented to American culture and its medical profession the evidence of their neglect in a major human experience: the care of the dying person.

"There's nothing more I can do for you, you're going to die." So said the doctor, leaving the patient, the nursing staff, and the family to fend as best they could with one of the fundamental issues of life. In contrast, a general practitioner, Dr. Merrill Shaw, himself soon to die of rectal cancer, wrote of his own dying process in a very different vein:

> The period of inactivity after a patient learns there is no hope for his condition can be a period of great productivity. I regard myself as fortunate to have had this opportunity for a "planned exit." Patients who have been told there is no hope need help with their apprehension. Any doctor forfeits his priesthood of medicine, if, when he knows his patient is beyond help, he discharges his patient to his own services. Then the patient needs his physician more than anyone else does. The doctor who says merely, "I'll drop in to see you once in awhile; there's nothing more I can do," is of no use to the patient. For the patient goes through a period of unnecessary apprehension and anxiety.

Research of the past decade on death and dying has now produced several thousand titles. Thus, in this chapter we shall allude to major areas of research, but focus on the major clinical aspects of care of the dying.

Cultural Antecedents

As Feifel has documented, the topic of death was culturally taboo in American culture until the past decade. That is not to say that death and dying were ignored, but rather what was repressed surfaced in the pornography of death. The lurid, perverse, and seeming compulsive preoccupation with death and dying themes has been obvious, reflected in a movie like *The Loved One*—a parody on the Forest Lawn cemetery in Los Angeles.

Parsons and Lidz observe that the Judeo-Christian heritage contributed greatly to the denial of death in Western civilization. Yet prior to the advent of modern medicine, the ravages of disease, war, and punishment continuously confronted people with death. The success of medical technology and the distant displacement of war has left many Americans with little direct contact with death until well into adult life. However, a number of factors converged to challenge our cultural denial. Medical advances prolonged life so that for the first time in our culture a major segment of aged remind us of the end of life. Medical advances prolong the lives of many who live among us while they die. New medical techniques of organ transplantation, dialysis, and radical medical and surgical therapies confront medicine and the culture with hard decisions about life and death. Thus, we have a greater degree of decision regarding when we die, although we have no more capacity to influence the inevitability of death than before.

Perhaps even more fundamental is the crisis in meaning. The challenge to traditional values and their religious supports has left many facing an existential dilemma of providing purpose to keep on living. Thus, modern medicine becomes devoted to the preservation of life, while death is viewed as an intrusion into a scientific quest for eternal existence. The maintenance of life per se as the ultimate value is reflected in various science fiction fantasies, such as the movie *2001,* and the interest in cryogenic methods of preserving life. As an example one medical scientist stated: "I, myself, tend to adhere to the concept of death as an accident, and therefore find it difficult to reconcile myself to it for myself or for others . . . people do not forgive themselves easily for having failed to save their own or others' lives."

Cultural and medical awareness of the problems of dying has not come directly to us. Our recent history begins perhaps with the studies of loss and bereavement heralded by Lindemann's paper on grief in 1944 and reemphasized by Engel's distinction between healthy grief and pathological mourning. A more direct approach marked the popular exposes and analyses of American funeral practices.- Then, beginning in 1959 with the work of Feifel, numerous books took up the topic of death, although usually in a philosophical or theoretical vein.'-- the problem of suicide and its prevention finally brought attention to problems of dying, rather than death itself, culminating in sociological studies on the context of dying.- But only recently have we come to address fully the problems of caring for the dying. Thus, this evolution of research seems to reflect the difficulty in confronting death that professionals share with their culture.

Attitudes about Death

Our behavior throughout life is determined by our culture, and the same is no less true of our behavior in dying. Primitive cultures did not perceive death as a final biological state. The worlds of the gods and various concepts of continuing life provided a sense of continuum between this current life and extensions into other forms of existence. In contrast, classic Western cultures held a fatalistic view of death as the inevitable termination and destruction of existence.

At present we observe four different cultural attitudes toward death: death-denying, death-defying, death-desiring, and death- accepting. American culture has been generally death-denying. It has been suggested that physicians fail to provide assistance to the dying because of their unresolved conflicts about death. Feifel reports that physicians tend to deny death more than other segments of our society. Although the choice of medicine as a career may partly reflect unconscious conflicts over, and denial of, death, the attitudes of physicians may be more determined by the general denial of death in American culture.

Psychiatrists, too, share in the same cultural denial, although they use more abstruse mechanisms. Thus, Wahl observed:

> It is interesting also to note that anxiety about death, when it is noted in the psychiatric literature, is usually described solely as a derivative and secondary phenomenon, often as a more easily endurable form of the "castration fear" ... it is important to consider if these formulations also subserve a defensive need on the part of psychiatrists, themselves.

We can observe the threat of death in many psychotherapeutic situations: how a patient's threat of suicide cows the therapist; how the psychiatrist puts himself in physical danger with a dangerous patient without noting the real danger; the therapist's reluctance to allow a patient to expose his deepest threatening fantasies and psychotic thoughts that intimate the annihilation of personality. How often as a young psychiatrist I despaired of working with prisoners with a life sentence or facing death. How dead these men seemed to us with our bright anticipatory lives.

The denial of the anxiety of death is perhaps best exemplified in the avoidance of death among professionals. Most typically, in a hospital setting physicians and staff are very apprehensive about talking with dying patients —even more apprehensive about a psychiatrist's talking with a dying patient.

They will suggest that the dying patient will become nervous, anxious, hurt, upset, injured. Yet Kubler-Ross reports that only 2 per cent of 200 dying patients rejected an opportunity to discuss their dying, and she observed no adverse reactions in her interviews with dying patients. But she also reports that many professional personnel became upset watching interviews of dying patients. In my experience I have found most dying patients not only willing but desirous of discussing their illness and dying. To be sure they discuss these issues in guarded and partial ways at times, but they want to deal with their life at the moment. On the other hand, like Kubler-Ross, I have observed nurses become so anxious over a dying patient that they could not function, physicians cry out in despair during an interview, and psychiatrists angrily denounce the inhumaneness of talking with a patient about his dying. These observations suggest that the fears about the dying patient voiced by the personnel are projections of their own fears about handling the process of dying.

The death-defying attitude is rooted in our traditional Judeo-Christian heritage. St. Paul sounds the keynote: “death is swallowed up in victory. O death, where is thy sting? O grave, where is thy victory?” (I Corinthians 15:54-55). A more poignant note is given by Dylan Thomas—“Death, Be Not Proud” and “Rage, rage against the dying of the light.” Or consider those who have fought for causes, ideologies, families, or country, in defiance of the fact that they die in the doing.

The death-desiring attitude is perhaps less common in our culture, reflecting individual rather than cultural dynamics. A desire to die may be a means to resolve life conflicts, or to kill the self for revenge or retaliation. The desire not to live may occur among the severely disabled, debilitated, or unhappy elderly, who seek release and escape from the misery of life. In instances of neurotic or psychotic fantasy, one may seek reunion with loved ones in the magical union of death. For example, in *Othello* and in *Aida,* the lovers will be reunited eternally in death.

In contrast to the above attitudes that sequester death apart from life, there are the death-accepting attitudes, in which death is seen as a part of life and an integral part of existence. Death as the concluding episode of one’s life plan is eloquently described by Bertrand Russell:

> An individual’s human existence should be like a river—small at first, narrowly contained within its banks, and rushing passionately past boulders and over waterfalls. Gradually, the river grows wider, the banks recede, the waters flow more quietly, and, in the end, without any visible break, they become merged in the sea, and painlessly lose their individual being.

This view of death as the conclusion of a process does contain a certain romantic quality. As Schneidman points out, however, this view of death tends to make accidental or early death a tragedy—the romantic life has been cut short!

A very different death-accepting attitude is seen in various existential philosophies, which posit death as a central issue in the manner with which we go about the process of living. For some existentialists dying does not refer to that one event of physiological end, but rather to the potential threat to one’s own non-being. Thus, Heidegger asserts that we are faced with a basic anxiety about our authentic potentiality for-Being-in-the-world. If we do not face and resolve our existential death anxiety, we are not free to live. In a similar vein Norman O. Brown argues in *Life Against Death* that neurosis arises from the incapacity to die. Once freed from avoiding death we can joyously embrace life.

These broad cultural attitudes toward death and dying have received less attention than the psychological and sociological factors. Some research has focused on the role of philosophical and religious attitudes in different patients’ styles of coping with dying. This work has proven inconclusive thus far. Patients with strong philosophical or religious convictions do not necessarily cope with their dying according to their intellectual affirmations. Clinically it appears that dying patients cope with the stress of dying in the same way they have previously coped with life stresses. Thus, emotional coping styles assume primacy over intellectual coping styles.

Meaning of Death throughout the Life Cycle

The meaning of death and the experience of dying varies throughout the life cycle. Thus, the clinician must approach the dying patient in terms of the patient’s life stage.

For the infant and very young child dying is primarily the physical discomfort of the disease process and the treatment procedures. For the toddler and preschool child there is little concept of a personal death. For this child the primary fear is that of separation from the nurturant parents. Often, too, a child of this age may perceive illness as a punishment and hospitalization as parental rejection. For the grade school child dying poses a disruption in his developing interpersonal relations and his growing sense of identity; to the adolescent dying poses a frustration and defeat of the newly competent youth, who is just coming to mastery of his life.

For the active young adult dying poses a problem of narcissistic loss—loss of one’s healthy body, of one’s active, striving self-image, of one’s investment in a growing family and life plan. Whereas for the middle-aged adult dying more often poses a concern for one’s ongoing life involvement with loved ones and spouse. For example, a 50-year-old woman was quite agitated in the hospital because she feared she would die before she got home and saw that her house was in order, care for her children arranged, and her husband made comfortable about her departure.

For the aged dying faces one with the history, consequences, and meaning of one’s life. As Willie Loman says in *Death of a Salesman,* “A man can’t go out just the way he came in. He’s got to amount to something.” I am impressed by the perseverative reminiscence engaged in by residents in retirement homes. They are not yet ready to die because they have not yet come to peace with their life. Erik Erikson summed up this life crisis as that of integrity versus despair:

> It is acceptance of one’s own and only life cycle and of the people who have become significant to it as something that had to be and that, by necessity, permitted of no substitutions . . . and that for him all human integrity stands and falls with the one style of integrity of which he partakes.

In addition, the elderly are faced with a large degree of social isolation, interpersonal deprivation, rejection for being deviant in our youthful society (i.e., old), and usually a high degree of “bereavement overload”—they are experiencing a rapid succession of losses of love relationships.

Death versus Dying

Death is not a problem of life. Death is not lived through. Although there are case reports of patients who have returned to life after experiencing a sense of death, such events do not address the major issue of the dying process.

Death is not amenable to treatment. But the process of dying is very much a part of the person's life. When death is seen as an inevitable event coming soon, we may feel a sense of defeat and therefore ignore the period of living until the death event. This is the period of living-dying. The human dilemma of this living-dying process was brought home to me personally by a letter from a lady unknown to me:

> Dear Dr. Pattison: Quite by accident I read your treatise on dying. Because I am so grateful for your guidance I am writing not only to thank you but to suggest that the article be made available to relatives who care for patients. . . . My husband has been treated for chronic glomeruli nephritis for nine years. For the past five years, he has had biweekly dialysis which equates to a living-dying stage of long duration. In these times, when there is no doctor-patient relationship in this type of indirect care, the entire burden of sharing the responsibility of death falls to the member of the family. . . . Your listing of the fears was so apparent when I read your paper, yet when my husband experienced them I was unprepared to see them or even acknowledge them. When a patient is accepted on a kidney program, he knows he is dying. Would it not be a kindness to the person caring for him to know his fears and how to help?

As said so clearly by his wife, the period of living-dying is most important to the patient, his family, and to professionals, and this dying process may last hours, days, weeks, months, even years.

The knowledge of his forthcoming death often produces a crisis in the life of the patient. During the period of acute crisis there is an increasing anxiety that will reach a peak of tolerance. No one can continue to function long at peak anxiety, and, therefore, the patient will call into play mechanisms to cope with the crisis of death knowledge. If the person successfully deals with this knowledge crisis, he can proceed in an integrated pattern of dying. But if the person does not deal with this crisis, his dying can become a disintegrative process with the use of many dysfunctional mechanisms. Thus, we can plot out what Straus and Glaser call the “trajectory of dying” (Figure 34-1).

The knowledge of death as a crisis event can be analyzed in terms of five aspects of crisis:

1. This stressful event poses a problem that by definition is insolvable in the immediate future. In this sense dying is the most stressful crisis because it is a crisis to which we bow, not solve.

2. The problem taxes one’s psychological resources since it is beyond one’s traditional problem-solving methods. One is faced with a new experience with no prior experience to fall back on, for although one lives amidst death, that is far different from one’s own death.

3. The situation is perceived as a threat or danger to the life goals of the person. Dying interrupts a person in the midst of life; and even in old age it abruptly confronts one with the goals that one set in life.

4. The crisis period is characterized by a tension that mounts to a peak, then falls. As one faces the crisis of death knowledge,

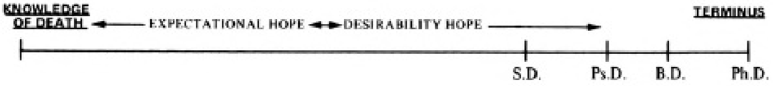
there is mobilization of either integrative or disintegrative coping mechanisms. There is a degree of diminishing anxiety as one approaches death. But the peak of acute anxiety usually occurs considerably before death.

5. The crisis situations awakens unresolved key problems from both the near and distant past. Problems of dependency, passivity, narcissism, identity, and more, may be reactivated during the dying process. Hence one is faced not only with the immediate dying process but also with the unresolved feelings from one’s own lifetime and its inevitable conflicts.

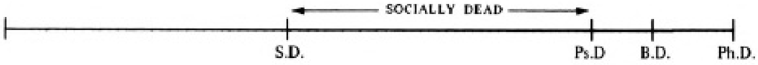
This crisis of knowledge of one’s own death may be experienced as an overwhelming, insuperable feeling of inadequacy—a potential dissolution of self. There is bewilderment, confusion, indefinable anxiety, and unspecified fear. Death confronts the person with a crisis to which there is seemingly no answer, and the ensuing anxiety makes it difficult to distinguish and cope with the various aspects of the dying process. But here lies the opportunity to intervene, for although we cannot deal with the ultimate problem of death, we can help the person to deal with the various parts of the process of dying.

Figure 34-1: Variations in Temporal Proximity of Aspects of Death

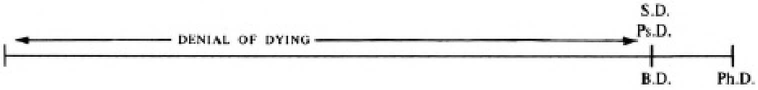
1. Ideal Proximity. (note termination of hope)



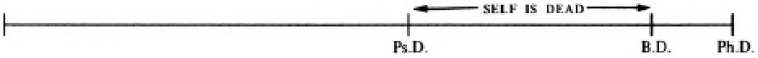
2. Social Rejection of Patient.



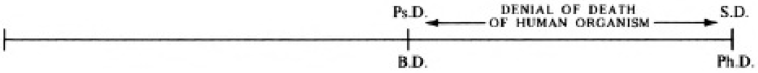
3. Social and Patient Rejection of Death.



4. Patient Rejection of Life.



5. Social Rejection of Death with Artificial Maintenance.



B.D. = Biological Death

Ph. D. = Physiological Death

Ps. D. = Psychic Death

S. D. = Sociological Death

By focusing upon the various aspects of the dying process, we can assist the dying person to resolve the crisis in a fashion that enhances his self-esteem, dignity, and integrity. The dying person can then take pride in having faced his crisis of dying with hope and courage.

Parts of the Dying Process

Now let us consider each of the fears that face the person in the experience of dying.

Fear of the Unknown

Freud suggested that the unconscious does not recognize its own death but regards itself as immortal. “It is indeed impossible to imagine our own death; and whenever we attempt to do so, we can perceive that we are, in fact, still present as spectators.”

In this view we fear the unknownness of death. On the other hand, the work of Lifton and others suggest that death anxiety harkens back to the most primordial feelings of helplessness and abandonment. The fear of the unknown is not the unknown death but the unknown of annihilation of self, of being, of identity. Leveton describes this sense of “ego chill” as “a shudder which comes from the sudden awareness that our non-existence is entirely possible.”

This unknown cannot be processed within the self. Lifton suggests that perhaps all of us must to some extent defend against this fear by a process of psychic closing off. Although this may not be totally effective, it may enable the person to focus on other aspects of his dying with which he can cope. Here a degree of denial and isolation may be quite appropriate to avoid unnecessary preoccupation. Janice Norton describes this process clearly in a dying woman:

> She told me that her only remaining fear was that dying was strange and unknown to her, that she had never done it before. . . . She no longer worried about what was to happen to her after death. . . . She felt that she might be unnecessarily concerned with the actual process of death itself.

Fear of Loneliness

When one is sick there is a sense of isolation from oneself and from others, reinforced by the fact that others tend to avoid a sick person. This mutual withdrawal is even more evident when a person is dying. The isolation attendant to dying is not only a psychological phenomenon but is also a reflection of our urban culture and medical technology that has dehumanized and mechanized the dying process. No longer does our culture afford us the luxury of dying amidst our family and belongings; over 60 per cent of deaths now occur in the impersonal, isolated hospital room. One of the functions we have defined for hospitals in our society is that of dying places. Yet major sociological studies of hospital nursing and medical practices demonstrate that the hospital staff use a variety of denial mechanisms to preclude awareness of dying among themselves, the family, and the patient.' Therefore, most people experience their dying within a context of "closed awareness." As a consequence everyone engages in elaborate maneuvers to maintain the closed atmosphere, thereby preventing the staff, family, and patient from openly facing the dying process and responding in a humane and helpful manner.

This closed context effectively isolates the patient from communication. In addition, family and staff begin to avoid the patient, visit less frequently, answer call lights more slowly, and minimize the duration of contact with the dying patient. The impact of all this isolation is a sense of human deprivation. As shown in many experiments the human deprived of contact with other humans quickly disintegrates and loses his ego integrity. For the dying person his isolation and human deprivation sets the stage for a type of anaclitic depression. This is not the depression of the loss of a loved one, but the loss of necessary human nurturance. Without this support one rapidly falls into the confusional syndrome of human deprivation that we term loneliness. It seems that this fear of loneliness is paramount when the person first faces the prospect of death and anticipates isolated rejection during dying.

Fear of Loss of Family and Friends

The process of dying confronts the person with the reality of losing one’s family and friends through one’s own death just as much as if they were dying. Hence there is a real object loss to be mourned and worked through. Rather than denying this real separation and preventing the grief work, it is possible for both the patient and his family to engage in “anticipatory grief work.” The completion of such grief work may allow the patient and his family to work out emotionally their mutual separation and part in peace. This is akin to the Eskimo custom of having a ritual feast of separation before the old person steps onto the ice floe and waves goodbye as he floats off to die in the sea; similarly, in the Auca tribe of South America, after a farewell ceremony, the old person leaves his clan to climb into a hammock to lie alone until he dies. Failure to recognize this real object loss may block the normal grief process and make it difficult for the dying person to distinguish between his own problem of death and the healthy process of grief that can be accomplished before death.

Fear of Loss of the Body

Since our bodies are so much a part of our self-image, when illness distorts our body, there is not only loss of function but a psychological sense of loss of self. This narcissistic blow to the integrity of the self may result in shame, feelings of disgrace and inadequacy, and loss of self-esteem. As before, the patient can be helped to mourn this loss actively and retain a sense of integrity in the face of separation from parts of oneself. Since we humans do not tolerate ambiguity well, it is more difficult to tolerate ambiguous distortion of body function. Patients will tolerate externally disfiguring disease better than internal disease because one can see clearly the loss of structure and function. Although external disfigurement may seem ugly, it poses less threat than the unknown and unspecified processes that the person cannot see and keep track of. Hence the failing heart or hidden cancer will provoke more anxiety than the external symptoms of disease.

In addition to the narcissistic loss, the patient may perceive his self as disfigured and unlovely, hence see himself as unlovable. Then the dying patient may try to hide his unlovely self from his loved ones, for fear that his family will likewise despise his ugly self, reject him, and leave him alone.

Fear of Loss of Self-Control

As debilitating disease progresses one is less capable of self-control. This is especially true when one’s mental capacities are also affected. As shown in studies of brain-damaged persons, the actual functional deficit may be less problematic than the reaction to the perceived loss of control.

This problem is particularly acute in our society, which has placed strong emphasis on self-control, self-determination, and rationality. As a result most people in our culture become anxious and feel threatened by experiential states that pose loss of control or consciousness. This is reflected in our social ambivalence over the use of psychedelic drugs and alcohol, which produce states of diminished control and consciousness. In contrast to Eastern mystical experiential states, it is rare that Americans experience any sort of self- acceptable loss of control. Thus, when they come to the experience of dying, the loss of control of the body and the diminished sense of consciousness may create anxiety and fear and poses a threat to the ego. One is placed in a position of dependency and inadequacy so that in a sense the ego is no longer master of its own fate nor captain of the self.

Therefore, it is important to encourage and allow the dying person to retain whatever authority he can, sustain him in retaining control of daily tasks and decisions, avoid shaming for failure of control, and help the person to find reward and integrity in the exercise of self-determination available to him.

Fear of Pain

Although there are both cultural and individual differences in the response to pain, there is a more important distinction between pain and suffering. A certain level of awareness of self and one's body is a necessary precondition to suffering. This self-awareness may either enhance or diminish the sense of suffering. One may deal with suffering by providing temporary or partial oblivion to pain and hence diminish suffering. This is the typical medical response to pain in the dying patient. But this oblivion approaches and may be humanly indistinguishable from death. The other alternative is to diminish suffering through awareness and understanding. Bakan suggests this is a more humanistic approach to suffering in that it retains human dignity and integrity, allowing the patient to understand his own pain and resolve his conflicts over it. This proposition is borne out clinically: pain relief is not merely a function of analgesic medication but is most influenced by the patient’s own attitude toward his pain. The fear of pain is not just a physical fear, but a fear of suffering, a fear of the unpleasant, of the unmanageable, of the unasked for. Senseless pain is perhaps intolerable. On the other hand, pain may be accepted and dealt with if that pain does not mean punishment or human suffering. People will not suffer long, but they will endure pain.

Fear of Loss of Identity

The loss of human contact, the loss of family and friends, the loss of body structure and function, the loss of self-control and total consciousness, all threaten the sense of one’s identity. Human contacts affirm who we are, family contacts affirm who we have been, and contact with our own body and mind affirm our own being self.

We can see that the dying process faces the person with many threats to self-identity. How does one maintain identity and integrity in the face of these forces of dissolution? Bowers et al. conclude that: “When life cannot be restored, then one can accept the fact with a meaning that gives dignity to his life, and purpose even to the process that is encroaching on his own vitality.” Willie Loman, the salesman, speaks of his own death: “A man must not be allowed to fall into his grave as an old dog.” It is not that we die, but rather how we die. The tasks are to retain self-esteem and respect for the self until death, to retain the dignity and integrity of the self through the process of living we call dying. If the person cannot sustain his ongoing sense of self, then he may fall prey to despair, the loss of self-esteem, the failure to respect oneself for what one has been.

One mechanism for the maintenance of integrity and identity comes from continuing respect and affirmation from the family and professional staff. This reaffirmation can continue to reflect to the dying person who he is.

Another aspect of identity comes from the sense of continuity, reinforcing one’s identity through the maintenance and continuity of one’s life via one’s family and friends. One can see identity in one’s children, life’s work, and in the bequeathing of one’s possessions to others. This is acted out in the leaving of a will and, in a more general sense, by leaving parts of one’s body, such as in eye banks, bone banks, and the like. This personal sense of continuity was illustrated by a middle-aged man who was dying of lung cancer. I had spent much time with him during his dying and talked about both his life and my budding career. At one point the surgeons wanted to perform a biopsy. He refused unless I gave permission. I explained to him that the biopsy would not change his disease but might aid in my understanding of his disease. Then he was happy to comply, feeling he could give me part of himself that I would carry with me in my professional life. He had given me part of himself to remain with me after his death.

Still a third mechanism of identity maintenance that occurs is the desire for reunion with loved ones who have died before or who will die and join one. These reunion fantasies include the sense of return to the primordial mother figure as well as reunion with specific loved ones. There will be reunion with one’s parentage and one’s progeny. Hence one can place oneself at one point in the continuity of ongoing human relationships, of which man’s death is merely a point in a more universal sense of existence.

Fear of Regression

Finally there is a fear of those internal instincts within oneself that pull one into retreat from the outer world of reality, into a primordial sense of being where there is no sense of time or space, no boundaries of self and others. Throughout the ego fights against this internal regression into selflessness. Freud called it Thanatos—the death instinct. Despite the metapsychological ambiguities of this concept, we can appreciate the phenomenological sense of this experience in the everyday universal experience of awakening in the morning. As the alarm rings we drowsily douse the noise, turn over, feel the immense weight of our sleep pulling us back into slumber. We luxuriate in the indefinite sense of our body boundaries, the relaxation of our awareness, the freedom from the demands and constrictions of the real world awaiting our awakening. And with exquisite pleasure we allow ourselves to float back off into a timeless, spaceless, selfless state of nonbeing. Certain religious mystical experiences, psychedelic experiences, and body awareness exercises produce similar altered states of consciousness. For the most part, however, most people in our culture encounter great difficulty in allowing themselves to enter these regressive states, much less experience such states as enjoyable rather than anxiety- and fear-producing.

For the dying person, especially as he approaches his terminal state with obtundation of body and mental awareness, such a sense of regression may be very frightening. He may fight against the regression to hold onto the concrete, hard reality-boundedness of himself. This may produce the so-called death agonies —the struggle against regression of the self.

In the attempt to attenuate this fear of regression, some ten years ago investigators began the experimental use of LSD and associated psychedelic agents. ” Their rationale was to provide the dying patient with an ego-syntonic drug experience that was in itself pleasurable to the dying patient and might provide an anticipatory experience of acceptable ego regression. In the main these expectations were not consistently obtained, and there is little current interest in the procedures.

Nevertheless, the psychedelic experiments did serve to call attention to the problem of terminal regression and its management. Clinical concern here shifts from helping the patient face reality to helping the patient turn away from reality. With support and encouragement the patient can approach an acceptance and surrender to the process of renunciation of life and return to a sense of union with the world out of which he has sprung. Then psychic death is acceptable, desirable, and at hand.

Sequence of Dying

Above is sketched out a clinical outline of major events in the dying process of the patient. First, the patient is faced with the seemingly impossible crisis of knowledge of death, which threatens to overwhelm the self. Mankind seems to have always recognized that no one has the capability to face this crisis alone, for we develop cultural customs whereby we actually and literally help people to die. Given our interest, support, and guidance, the dying person can face death as an unknown with the realization that he cannot know, and instead he can turn to consider the processes of dying that he can know and deal with. If not deprived of human contact, he can learn to endure the inevitable degrees of separation without loneliness. He can face the loss of relatives, friends, and activities if he can actively mourn their loss where his grief is defined and accepted. He can tolerate the loss of body structure if others accept that loss with him. He can tolerate the loss of self-control if it is not perceived by himself and others as a shameful experience and if he can exercise control where feasible. He can tolerate pain if he can see the source of pain and define the nature of his suffering. He can retain dignity and self-respect in the face of the termination of his life cycle if he can place his life in perspective within his own personal history, family and human tradition. If this is accomplished, he can move toward an acceptable regression where the self gradually returns to a state of nonself.

In this sequence of dying I have focused on the major psychological conflicts that face the dying patient. Others have suggested that there are specific psychological phases through which the patient passes. For example, Kubler-Ross suggests five stages: denial and isolation, anger, bargaining, depression, and acceptance. However, in my own experience and review of the literature I am less impressed by the uniformity of dying experiences than by the divergency. Further I have observed a tendency among clinicians to ignore the actual conflicts and needs of the patient by viewing dying as a stereotyped process. Also I have observed that clinicians may push patients to handle dying the way the clinician might handle his own dying, or the clinician may push the patient to move through some preconceived set of stages of dying. Instead, clinical judgment requires an assessment of the conflicts and needs of the patient, which will vary with his age, values, coping mechanisms, family relationships, behavior of hospital staff, and other factors.

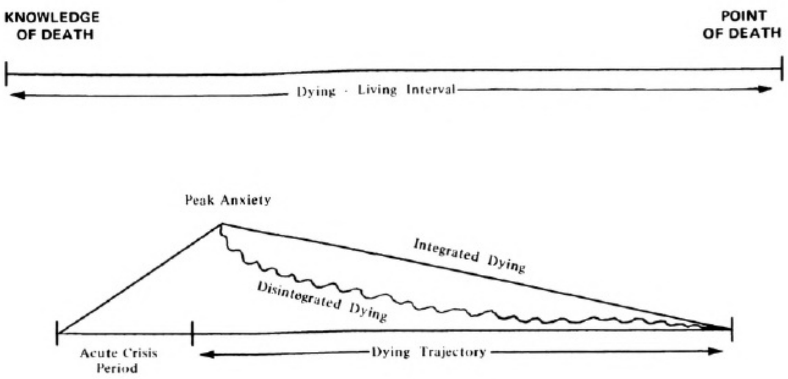
There is, however, a pattern of change over time in the trajectory between knowledge of death and death itself. Glaser and Straus outline four types of “death expectations”: (1) certain death at a known time; (2) certain death at an unknown time; (3) uncertain death, but a known time when the question will be resolved; (4) uncertain death, and an unknown time when the question will be resolved. Each of these expectational sets has a different effect upon the patient and his interaction with others. As the course of the illness becomes clear, that knowledge does force the patient and the staff to reckon with the impending death.

This expectational set plays an important role in the sense of hope. Stotland makes a helpful distinction between two types of hope: hope as expectation and hope as desire. At the outset each dying patient holds hope for himself in terms of the expectation that he may not die. As that expectational set is dissolved, the patient may deny the inexorable process by clinging to expectational hope.

On the other hand, the patient may be assisted to change from expectational hope to desirable hope; that is, it would be good to live but it is not to be expected. This latter hope can play a role in the maintenance of integrity. However, as indicated in our discussion of regression, even this desirable hope might optimally give way to acceptable regression. For this reason Cappon suggests that hope (in the desirability sense) should not cease until shortly before psychic death.

This leads us to a brief outline of four aspects of death itself. First is sociological death, that is, the withdrawal and separation between the patient and significant others. This sociological death often occurs days and weeks before terminus if the patient is left alone to die, or it may precede terminus as a gradual and seemingly imperceptible diminution. Second is psychic death, which occurs when the person accepts his death and regresses into himself. Such psychic death may proceed coincident with the diminution of actual psychic function. On the other hand, psychic death can occur earlier than terminus as in cases of voodoo death or in patients who predict their own death and refuse to continue living. Third is biological death in which the organism as a human entity no longer exists, such as in irreversible coma, where the heart and lungs may continue to function with artificial support. And fourth is physiological death, which occurs when viable organ system function ceases. As illustrated in Figure 34-2 these four aspects of death are not necessarily closely related in time, thus often producing many problems in patient care and dying decision making. Optimally our task in caring for the dying is to coordinate psychological and medical care so that all four aspects of death converge in close proximity.

Figure 34-2: The Dying–Living Interval



Help in the Experience of Dying

If the dying person is provided the opportunity and assistance, it is possible for the experience of dying to be appropriately integrated into the process of living. Weisman and Hackett'' suggest that we consider how to help a patient toward an appropriate death. They offer four criteria for an appropriate death that closely approximate the various conflicts discussed before:

1. Conflict is reduced

2. Compatibility with the ego ideal is obtained.

3. Continuity of important relationships is preserved or restored.

4. Consummation of basic instincts and wishes of fantasy reemerge and are fulfilled.

The concept of an appropriate death is based on the clinical goal of adaptation rather than on an ideal goal. That is, we seek to help the patient integrate his dying into his life according to the style, meaning, and sequence of his life. Thus, the criteria of an appropriate death will be fulfilled in different ways for each patient. Each man's appropriate death will be different, but his dying will be appropriate to him.

Helping the Dying Patient

To assist the patient in his dying, certain patterns of assistance can be summarized in accordance with the conflicts and fears discussed above. We can share the responsibility for the crisis of knowledge of death, so that the patient can deal with the first impact of anxiety and bewilderment. We can clarify and identify with the patient the difference between death and dying and specify the processes of dying with which the patient can deal. These processes of dying are the realities of day-to-day life. We can make continued human contact available and rewarding. We can assist in working through the grief over the realistic losses of family and body image while retaining communication and meaningful relationships with those who will be lost. We can assume necessary body and ego function in the face of diminished self-control and pain, without incurring shame or depreciation for the person, thus helping him maintain integrity and self-respect. We can encourage the person to work out an acceptance of his life situation with dignity so that gradual regression can occur without conflict or guilt, while expectational hope can be transformed into desirable hope and relinquishment of self can be allowed.

Helping the Staff Who Care for the Dying

In most instances the psychiatrist does not assume major responsibility for the dying patient. Although there are occasions when there is need for brief psychotherapy or crisis intervention by mental health professionals, the more general task is to provide adequate consultation to medical and nursing staff, as well as educational and organizational assistance to enable the hospital as a social unit to deal more adequately with its function as a dying place.

Because of the major organizational problems in dealing with dying, Glaser and Straus offer four major recommendations for institutional change, each of which should be of concern to the psychiatrist:

1. Training for giving terminal care should be greatly amplified and

deepened in schools of medicine and nursing.

2. Explicit planning and review should be given to the psychological, social, and organizational aspects of terminal care.
3. There should be explicit social psychological planning for phases of the dying trajectory that occur before and after residence in the hospital.
4. Medical and nursing personnel should encourage public discussion of issues that transcend professional responsibilities.

To provide such assistance to fellow professionals, it is incumbent that the psychiatrist first deal with his own conflicts and countertransferences. Numerous case reports indicate that the dying patient often abruptly confronts the psychiatrist, who becomes immobilized until he can resolve his own internal conflicts.- In his parable, *The League of Death,* Allen Wheelis shows us we cannot help until we no longer fear and flee from death.

In addition, addressing the problems of the dying requires a shift in the usual therapeutic orientation. Typically we focus on the movement toward a fuller engagement of life in psychotherapy, but here we move into the unaccustomed orientation of disengagement. The more traditional techniques of ongoing psychotherapy are less appropriate, and we must call upon our recently developed skills of brief psychotherapy. In addition, work with the dying often calls for skills in family therapy, for the clinician must address the interpersonal aspects of the dying process. Finally the clinician should be able to utilize group therapy skills. In certain groups of patients with lingering fatal disease, the use of short-term group sessions may provide an effective means of modifying patient attitudes and behavior''

To enhance staff management of the dying requires the active involvement of the psychiatrist, therefore, not only with the dying but with those who care for the dying. Weisman and Kastenbaum have provided schematic procedures for what they call the “psychological autopsy.” They propose that hospital staff hold an autopsy evaluation of the dying process, just as we currently conduct pathological autopsies. Through such a dispassionate scientific-medical method we may be able to assess distortions that occur in the dying process and consequently work out staff consensus for more effective management. Such procedures, or similar joint staff work on the problems of dying, may offer the vehicle for sound organizational improvement.

Helping the Family of the Dying

Since the majority of deaths occur in the hospital, the consulting psychiatrist and the staff may neglect the needs and relevance of the family because they are not part of the organizational structure. It is noteworthy that in the extensive literature on dying there is very little said about care for the family. Yet they merit concern on two counts. First, they are integrally related to the manner in which the dying person will experience his dying. Second, they are themselves vulnerable and affected by the dying process, and they, too, may need assistance to live through the experience of dying in a healthy manner.” Just as with the patient, the family must face the anxiety and apprehension of the knowledge of the death crisis. They, too, must face the separation and loss, so that they can reciprocally work through the anticipatory grief of loss. They must make specific decisions in regard to children, home, finances, and belongings. And they must work out the meaning of their lives reconstituted without the dying person. In this arena we have generally neglected the contributions that the funeral director and the minister can make. These people often have more intimate contact with the family than the medical staff does. Consultation, collaboration, and educational work with these community care agents should become a part of the overall pattern of care for the dying.

Preventive Aspects of Dying

At the outset I suggested that the problem of death is not solely an issue of management of the dying process, but involves the whole texture of human existence. A half century ago we learned that failure to reckon openly with sexuality gave rise to neurotic distortions of existence. In similar vein I have suggested that failure to reckon openly with death in our time may give rise to neurotic defenses against awareness of death in our lives. If we can speak of sexual neuroses, it may be appropriate to speak of death neuroses.

Although there is little general agreement yet regarding the more general proposition of death neuroses, there is abundant clinical and experimental data on the impact of death and bereavement on personality adjustment. For example, Moriarty has recently summarized the effects of death in the family on subsequent personality development. He takes the position that experience with death in childhood poses serious trauma to the child, and, therefore, the child should be protected from exposure to death. This position, however, confuses psychic stress and psychic trauma. There is no doubt that death does impose a stress on the child, but that does not mean that such stress is necessarily traumatic. The psychic trauma may be an artifact of adult attitudes and adult reactions to death. Since we have not openly dealt with death as adults, it may be difficult to teach children how to deal appropriately with death. In fact, Eissler some fifteen years ago suggested that we should practice "orthonasia," that is, teach children about death as a part of life, so that children will learn how to incorporate healthy attitudes toward death into their coping repertoire and be adequately prepared to deal with death events in their own life cycle. Support for such preventive death education has been provided in recent publications.

A related aspect of prevention bears on the grief and mourning process.

The relationship between unresolved grief and neurotic depression syndromes has been amply discussed. This data have come primarily from patients with psychiatric symptomatology. Extensions of this process have been observed in recent epidemiological studies of bereavement. Such work demonstrates significant evidence of “bereavement morbidity.” That is, there is an increased physical and emotional morbidity rate among the family and friends of the deceased.- Thus, there is a penumbra of psychopathological reactions that surround a person’s death. Prevention of such “death contagion” presents us with a major challenge in community mental health. One example of preventive intervention along these lines is the widow-to-widow program, in which the widow and her family are contacted after the funeral by the local mental health team, which provides assistance in their grief work and guidance in reintegration into normal life patterns. Other related preventive programs might include Parents without Partners programs, which provide a natural community group for single parents, and Big Brothers and Big Sisters programs, which provide parental surrogates for children who have lost a parent." Such programs can provide support during the normal grief process, provide new human relationships that can partly replace the lost person, and provide guidance toward health integration.

Summary

In contemporary culture death is viewed with a perverse and morbid curiosity. In the face of shifting pluralistic values, diminution of previously integrating religious values, and medical advances posing new types of death decision making, there are few reliable guidelines available to the layman and the professional in the management of the dying process. We are in the midst of a reevaluation of death in our culture. Death per se cannot be changed, but we can change the patterns of dying. Help in the dying process must focus on three areas: help to the dying patient, help to the hospital staff, and help to the person's family and friends. Since dying is a universal human experience, it merits the serious attention of the psychiatric profession. As with all human experience the clinician must first confront death within himself, and then he can begin to practice the high therapeutic art of helping people to die.

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