CHANGING THE CULTURE OF DYING

A New Awakening of Spirituality in America Heightens Sensitivity to Needs of Dying Persons

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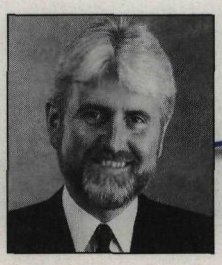

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The rapid development of medical technology and the steady expansion of institutionalized healthcare delivery have coalesced with deeply embedded American values to create a distinctive approach to dying and death in America. The laudable successes of technological medical care unfortunately have further masked the inevitability of death in a culture that fails to accept death as an integral part of life.

Traditional American confidence in innovation, individual effort, and limitless progress has spawned the hope that even physical death might succumb to scientific progress, thereby discouraging reflection on the inevitability of death and its relevance to our lives. In America death is zoned off from everyday life. Indeed, "Death is a subject that is evaded, ignored, and denied by our youth-worshiping, progress-oriented society."[1]

Historian Arnold Toynbee captured the prevalent American attitude toward death: "For Americans, death is un-American, and an affront to every citizen's inalienable right to life, liberty and the pursuit of happiness."[2] In recent years, this dismissive and existentially arrogant attitude has shaped the experience of dying in America. The process today is characterized by three salient features: alienation, fragmentation, and diminishment.

Summary Americans increasingly believe there are material solutions to all problems. Though we once accepted death as a part of life, we now think that—with enough technology—death can be controlled and postponed. Throughout this century, we have moved the dying process from the home to institutional settings. But institutions have a tendency to push all care to its logical end, which leads to alienation, fragmentation, and diminishment.

Alienation is the result of the isolation and regimentation found in acute and skilled nursing care facilities. When care givers are indifferent to patients' pain, or do not know how to control it, they further impair the ability of dying persons to interact with others. Care for the dying person, "system by system, organ by organ," as is typical in institutional settings, fragments the dying process into a series of medical events. And, finally, institutionalized care often results in a diminishment of respect by care givers, who may come to view the dying person more as an object of academic interest than as a human whose spiritual needs may transcend physical ones.

Such behavior has begun to show us the human costs of denying death and is contributing to a reawakening of spirituality in this country. The devastating effects of alienation, fragmentation, and diminishment can be ameliorated by a heightened sensitivity to the dying person's spiritual needs. With the proper supports, the dying process can be relocated from institutions to the home. Specialized training can educate healthcare professionals about palliative care and human needs at the end of life. We can rehumanize dying persons by first rehumanizing their care givers, specifically addressing the issues of stress and burnout on the job.

Ultimately, the way we give care at the end of life reflects broader issues in U.S. culture. Only when communitarian values replace individualistic ones will resources be reallocated in a manner that best serves the most people. Only then will physicians, nurses, and other care givers receive rewards for supporting the dying person when tests and treatment are no longer needed.

Vivienne Flesher

DEATH AMERICAN-STYLE

Alienation Dying persons are alienated from friends, family, and the community by the enforced isolation and regimentation of acute care and skilled nursing care settings. They are often alienated from the very core of their conscious being by incompetent attempts to control their pain or indifference to that pain. They are further alienated when frustration, embarrassment, fatigue, guilt, and feelings of failure, resentment, or denial lead family, friends, and care givers to abandon them, often under the guise of protecting them. They are left adrift and helpless in a strange place.

Fragmentation The process of dying has become a series of medical events. Educators T. Patrick Hill and David Shirley argue that "medical technology tends to 'atomize' the patient, providing treatment system by system, organ by organ."[3] Dying is thus a fragmented series of interventions, rather than a harmonious human experience. "No one person attends to the dying patient," write ethicists David Thomasma and Glenn Graber. "Often different services are stacked up like planes at O'Hare field, waiting to attend the dying person."[4] These continuous medical procedures rupture the peace and continuity of a person's last days and prevent what has been until recently the personal and social ritual of death. "In ancient, medieval and even modern times," Thomasma and Graber observe, "most persons were able to sense' that they were dying. At that time, they would assemble their families and friends for some last words. . . . After talking and praying, the dying person assumed a ritual posture to await death."[5] The fragmentary nature and hectic pace of institutionalized care often force the dying person to forgo the continuity and comfort of a ritualized passage from life to death that is consistent with his or her culture and beliefs.

Diminishment Finally, the process of dying in America is sometimes reductionistic, especially in large teaching hospitals. A diminishment of personal respect easily infiltrates the clinical environment, generating a moral inattentiveness to the dying patient. The person becomes a "case," an object of academic interest that can be studied and manipulated. The reality of the deathward journey and the full range of human needs are overlooked.

Life-at-All Costs Mentality As we Americans drank deeply at the "fountain of youth" and considered the plausibility of a technologically engineered eternal life on earth, death was taken hostage by a life-at-all costs mentality. Postponing death has become the medical establishment's paramount value and driving force. The perpetuation of mere biological existence has begun to overshadow and truncate the human, integrative experience of death.

> THE ALIENATION, FRAGMENTATION, AND DIMINISHMENT ASSOCIATED WITH DYING IN AMERICA ARE ENEMIES OF THE HUMAN SPIRIT.

Common sense, as well as the painful and impoverished experiences of dying persons, their families, and their care givers, has steadily revealed the human costs of denying death its rightful place in life and the overly intensive use of medical technology. Consequently, organized resistance to the life-at-all-costs paradigm has been growing since the 1970s. Yet, even though the natural death, death-with-dignity, right-to-die, and assisted dying movements have made impressive gains in the realms of law, public policy, and even medical practice, death in America still comes hard. People are reluctant, or perhaps genuinely unable, to challenge and dismantle the prevailing modus operandi. As Hill and Shirley remind us, "This is a problem that no court ruling, no state or federal laws, and no change in the behavior or policies of the medical profession can easily alter."[6] Nothing short of an overarching cultural transformation can effect such change.

SPIRITUALITY AND DYING IN AMERICA

The transformation of the American culture of dying will require careful attention to a broad range of issues, including the spiritual dimensions of dying and death. The devastating effects of the alienation, fragmentation, and diminishment that currently characterize interactions with the dying can be ameliorated by a heightened sensitivity to spiritual needs. Increased sensitivity to the spiritual journeys of the dying person, family members, and care givers can soften the hard, empirical edge of clinical confrontations and transform them into genuine human encounters.

The human spirit has been described as "the part of the person that is most deeply concerned with feelings, with the need for meaning in life,

with convictions, belief systems, values, . . . 'ultimate things' like 'God' and 'life beyond death.'"[7] This dimension of life is often concealed and is less obvious than physical and mental attributes, but, as Erasmus argued:

> The most important is always the least conspicuous. A tree flatters the eye with flowers and foliage, and exhibits the massiveness of its trunk: but the seed, from which these have their strength, what a small thing, and how hidden. . . . And gems have been concealed by Nature in the recesses of the earth. What is most divine and immortal in man is inaccessible to perception . . . and also in the temperament of the physical body, while phlegm and blood are familiar to the senses and tangible, that which contributes the most to life is least patent, namely, the spirit.[8]

The life of the spirit, that is, spirituality, focuses on a person's relationship to life itself. It is the person's innate drive to find meaning and purpose in his or her life and destiny. Some level of spiritual awareness graces the life of each person. D. O. Dugan notes, "Whether one's need for meaning is met within formal religious structures, on the fringes, or outside religion altogether, 'man's search for meaning' seems to be fundamentally and universally human."[9]

Through our spirituality, we craft a framework of meaning that supports our movement through life by helping us interpret the significance of our conflicts, needs, and suffering and ultimately by supplying the resources we need to cope with our mortality. Moreover, our personal spirituality or search for meaning enables us to connect with other members of the human family. The empathy we feel for each other encourages us to build communities of shared meaning wherein we find affirmation and consolation as we confront the fundamental ambiguity of the human condition.

The alienation, fragmentation, and diminishment currently associated with the process of dying in America are enemies of the human spirit and impediments to a good death. They obstruct access to meaning when the human need for meaning is perhaps most intense. They are also antagonistic to a sense of community and thus barriers to the empathy one craves in extreme and uncertain circumstances.

Of course, we have no guarantee that any surplus of meaning will be disclosed in a revelatory flash just before death. On her deathbed, the story goes, Gertrude Stein was asked, "What's the answer?" She replied, "What is the question?" The moral is simple: "No revelation is received as an answer until the question has been experienced."[10] Whether or not something meaningful will be disclosed, shouldn't dying persons be given the necessary time and space to experience and grapple with their own core questions? Shouldn't they be offered one last chance for enhanced meaning that might ease them out of life and into death? Shouldn't the care of their dying, perhaps troubled, spirit be a priority?

A Spiritual Transformation

Any effort to understand and transform the culture and experience of dying in the United States must take into account the fundamental values that shape American life. The alienation, fragmentation, and diminishment that mark today's culture of dying are not accidental. They represent a pragmatic and largely materialistic value orientation.

Although the endemic denial of death militates against the emergence of a more spiritually informed approach to dying and death, there is an obvious thirst for spiritual renewal in the United States. One observer of the contemporary American scene has remarked on a "new awakening" of spirituality that "expresses itself in the most innovative, unexpected corners of secular culture."[11] Yet, he continues, "most of the institutions of American high culture are either against it or deny that it exists, even as they are being shaken by it at their very foundations."[12] The spectacular growth and economic impact of complementary therapies give clear evidence of this shift. Undoubtedly, some outrageous claims are being made in the name of spirituality, such as apocalyptic claims of groups like the Branch Davidians. Yet it can hardly be denied that a genuine revival of spiritual values is occurring, shaping different attitudes to the central issues of living and dying in America.

The three American cultural impediments to recognizing and supporting the spiritual journeys of patients and care givers—alienation, fragmentation, and diminishment—point to both *areas of concern* and *arenas for moral reflection, cultural reorientation, and pragmatic experimentation.* In these arenas, efforts are needed to regrind the lenses through which we view and understand care for dying persons.

Antidote to Alienation The antidote to alienating institutionalization is, of course, home-based dying. Most persons want to die at home, but go to institutions instead because of isolation, panic, and lack of support. Outside of home-based hos-

pices, which in many places are seldom an option, supports for dying persons who wish to stay home and for family members who wish to stay home with them are lacking. Insurance plans often do not provide the resources; families and neighbors often lack the time. What do we need, concretely, to enable more Americans to die at home?

Congregations, community groups and agencies, schools, and local television stations need to craft new images of where and how we die,

REHUMANIZING DYING PERSONS MUST FLOW FROM REHUMANIZING THEIR CARE GIVERS.

human images of death and dying outside of institutions. Such projects would build on the important inroads already begun by hospices and groups promoting the use of advance directives.

Antidote to Fragmentation One answer to the fragmentation experienced by institutionalized persons at the end of life is the development of healthcare professionals who acknowledge the integrity and lived experience of dying persons and who are willing to join them in their spiritual journey. Continuing to humanize the education and training of healthcare professionals will certainly help, as former Surgeon General C. Everett Koop is modeling in his innovative program at Dartmouth University Medical School. Internships in palliative care units may help. Continuing creative efforts to integrate ethics education into medical and nursing education are a must, particularly as time and resources for medical education continue to decrease.

Antidote to Diminishment With regard to the diminishment of dying persons, change will come when more healthcare providers have an emotional investment in caring for their patients. Dehumanizing the dying and other vulnerable persons is most often a symptom of care giver stress and burnout. Rehumanizing dying persons, therefore, must flow from rehumanizing their care givers. Healthcare needs constructive projects that demonstrate new forms of psychological and social support for professional care givers, along with projects that teach ways of coping with stress other than depersonalization and dehumanizing detachment.

A Shift to Communitarian Values

Ultimately, reawakening a sense of and support for spirituality in American culture is linked to a wider cultural shift currently under way: the transformation of individualistic values into communitarian values. Until that transformation is further along, the forces of alienation, fragmentation, and diminishment that assault dying persons and their care givers will continue to be fed, upstream, by a healthcare system that distributes more resources to those who enter institutions, where patients all too often become pawns in high tech's battle to the death against death itself. The more we distance ourselves from sophisticated technology, the more disorganized and unavailable support systems become.

We continue to need creative and constructive projects aimed at galvanizing us again as a community, commited to a vision of more justice in the access by all of us to basic healthcare. This vision would encompass chronic illness and dying and would reward physicians and nurses for supporting us over time, even when tests and treatments are no longer needed.

In the end, it is our spiritual journey as a people toward justice that will create the new social structures that will allow and encourage our human spirits to breathe and grow together when the night is come. □

NOTES

1. Elisabeth Kübler-Ross, *Death: The Final Stage of Growth,* Prentice-Hall, Englewood Cliffs, NJ, 1975, p. X.
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3. T. Patrick Hill and David Shirley, *A Good Death: Taking More Control at the End of Your Life*, Addison-Wesley, Reading, MA, 1992, p. 24.
4. David C. Thomasma and Glenn C. Graber, *Euthanasia: Toward an Ethical Social Policy*, Crossroad, New York City, 1990, p. 85.
5. David C. Thomasma and Glenn C. Graber, p. 85.
6. T. Patrick Hill and David Shirley, p. 35.
7. Daniel O. Dugan, "Essays on the Art of Caring in Nursing," *Nursing Forum*, vol. 23, no. 3, 1987-88, p. 110.
8. Erasmus, cited in Edgar Wind, *Pagan Mysteries of the Renaissance*, 2d ed., Faber & Faber, London, 1968, p. 222.
9. Daniel O. Dugan, p. 112.
10. John Shea, *Stories of Faith*, Thomas More Press, Chicago, 1980, p. 25.
11. Edgar Taylor, "Desperately Seeking Spirituality," *Psychology Today*, November-December 1994, p. 56.
12. Edgar Taylor, p. 57.