
Dying in America: Contexts and Problems

by Thomas A. Shannon

Examining contexts in which we die can lead to positive changes in the dying process in health care systems. Such restructuring includes adding a religious dimension for patients and families.

The contemporary context in which we die in America sets the tone for how we understand the dying process, how we respond to it, and with what resources we deal with it. Understanding these contexts in which our perception of death and our responses to it are shaped can lead to necessary changes in caring for those who are seriously ill and dying.

The Contexts of Dying in America

Life Expectancy

Probably the most important shift in dying has been the extended life span of Americans. In the late nineteenth and early twentieth centuries, average life expectancy was late forties or early fifties. Today, largely because of improvements in diet and sanitation, it is in the mid-seventies. The first impact of these changes is reflected in the dramatic decrease in infant mortality rates, with many of these infants going on to live a long life.

A consequence of increased life expectancy is that we now have time available to experience diseases that were once rare because individuals died before cancer or Alzheimer's or other diseases could manifest themselves. Consequently, while the first part of our lives is generally characterized by good health, the later part may be characterized by diseases or simply the aging process itself. While a decent life style and exercise may delay the effects of aging and improve the quality of one's life, nonetheless death comes.

Thus we exist in a paradox: we live longer, but our last days may be characterized by a lack of the quality of life we were accustomed to during earlier days.

Technological Advancements

A second major context is that during the last fifty years amazing advancements have been made in medicine and medical technologies. Because of these advancements, major childhood diseases essentially have been eliminated, the disappearance of smallpox being the most dramatic example. In addition, the discovery of antibiotics made possible the cure of many diseases. These scientific breakthroughs were augmented with stunning developments in medical technologies such as kidney dialysis, the ventilator, the pacemaker, and the heart-lung bypass machine that made heart surgery possible. When coupled with other advances such as organ transplants and resuscitation devices, one wonders what new frontiers are left to conquer.

However, no sooner do we develop an antibiotic to kill the virus than it begins to mutate. The primary danger now is that many viruses are becoming resistant to the current generation of antibiotics. Moreover, we are discovering that many of the technologies are half-way technologies, that is, they cannot cure the particular problem; rather they compensate for the problem. For example, the kidney dialysis machine cannot cure kidney failure but it can cleanse the blood of impurities. While certainly a gain, the person is dependent on the machine for the rest of his or her life.

Nevertheless, such medicines, technologies and surgical procedures have enabled health care providers to provide genuine benefits for many. These successes have nurtured a climate of intervention and an expectation of benefit. While such expectations have been realized for many, the limits of

such interventions are becoming more visible.

The Cost of Health Care

A third context for a discussion of dying is the cost of health care. While the physician has always been a business person with a fee-for-service relationship with patients, historically the decision to treat has not been based on cost but the best interest of the patient. The fee-for-service was softened by an ethos that encouraged acceptance of "charity" cases and public subsidy of the care of many patients. Hence, while a few patients could pay only a part or none of the fee, enough could and the physician was assured a decent living. Today, few physicians remain in private practice. Most are in some form of managed care and are employees of for-profit corporations. A critical shift here is use of incentives to make such corporations profitable, whether through bonuses to physicians who keep costs within the budget or through capitation funding, which provides a fixed amount for the number of procedures an HMO provides. The best interest of the patient may no longer be primary but may, in fact, be qualified by the financial interests of the physician, whether directly through a lack of a bonus or indirectly through fewer funds for various procedures. While most patients are not being harmed by this shift, the best interest of the patient is now in competition with other interests, whether private or corporate.

Fourth, American medicine is situated primarily in the context of *rescue* medicine, not preventive medicine — the *cure* of a disease, rather than *prevention* of the disease. The development of medicines, technologies, and surgical procedures, as noted above, partly explains this situation. When possible treatments are available, the tendency is to rush in with all available resources. This tendency results from years of *not* being able to treat certain illnesses, from a pragmatic culture that likes to problem solve, and also from the possibility of financial gain.

This tendency to rescue is understandable. Disease has caused human misery that, for a long time, people could do nothing about. Modern

medicine presented the possibility of actually benefiting people. Success, then, created a culture of intervention. Ironically, the economic shift in modern medicine is teaching us that prevention is much cheaper than cure. If through life style modification one prevents heart disease, the individual and society are both better off. Such interventions are not, however, as interesting and spectacular as the invention of a new technology or life-saving operation. Thus, while economics are driving us toward prevention, our culture still favors intervention.

Paternalism and Autonomy

Finally, we need to examine the bedrock value that has served as the foundation of medical ethics and medical practice for the last thirty years: autonomy. This principle was introduced into the practice of medicine to correct the dominant paternalism. Even twenty years ago, physicians often withheld information from the patient about his or her disease or status. Such information might be given to the patient's family, but many considered it harmful to the patient, a hindrance to the treatment plan, or something that might make the dying process more difficult.

Gradually, under the influence of both philosophical argument and court cases, autonomy replaced paternalism. Consequently, patients had to be informed of the diagnosis, prognosis, treatment options, and risks and benefits attached to each option. The patient made treatment decisions because the patient alone knew what was best for him or her, not the physician, the family, nor spouse. Thus medical decision making became centered on the patient, his or her values, perceptions about quality of life, and the burdens he or she could bear.

These five contexts have created an interesting culture in modern American medicine. On the one hand, prospects for intervening and effecting cures have never been better. On the other hand, the limits of such interventions are appearing and their cost is being questioned. Many physicians feel their medical judgments and professional independence is being compromised by HMOs who

must approve treatment plans. Patients are fearful of being shortchanged in their treatment. HMOs must explain that their desire to be profitable won't compromise physicians' judgments or patients' interests. And few trust each other. Finally, autonomy cuts across all these issues and puts the patient at the center, alone with his or her values. And even though autonomy is bumping up against financial limits, the decision of the individual is still the last word in treatment decision making.

The Shift in Dying

These five contexts have dramatically shifted the context of dying in America. Several resulting issues need to be examined.

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The impact of technology has played a critical role in shaping how many people die. As noted, many technologies that have an almost miraculous impact in saving lives also prolong the dying process because, in many cases, they only compensate for a bodily function but do not cure it. Dying is often prolonged, occurs in an intensive care unit, and the patient is often in pain. As the recent *SUPPORT* study has shown (The *SUPPORT* Principal Investigators 1995), this frequently happens in spite of patient and family wishes. In the *SUPPORT* study, intervention strategies were developed to ensure that patient wishes would be respected, but the strategies did not work. Even in the second phase of the study with more explicit strategies, little changed. Patients remained in the intensive care unit, continued to be medicated or maintained on life-support technologies, and were undermedicated for

pain control.

In this situation, it is difficult to bring spiritual resources to a patient, one who is frequently semi-conscious, unconscious, or in a coma. While some argue that persons in such a state — even the persistent vegetative state — might be able to comprehend or be somewhat responsive to human interaction, little evidence is presented for this. Daniel Callahan terms such a death, in such circumstances, a "wild death," one that occurs within a high-tech context, out of control, and with the patient unresponsive (Callahan 1995). Spiritual ministrations are mainly for the benefit of the family, not the patient. And while the family's needs are important, it is the patient who is in need of the ministry and who is now unable to receive it.

The concern, here, is that the transition stage in the dying process is often artificially prolonged by technology. The consequence is that further spiritual ministry to the patient is impossible because of his or her condition, and the agony of the family is prolonged. A goal, or benefit, of spiritual ministry or pastoral counseling during the dying process is to help all reach a sense of closure and, often times, acceptance of death. The prolongation of dying by technology frustrates this sense of closure both by extending the dying process and removing the patient from further ministrations by both family and ministers.

Second, cultural isolation of the dying, an unintended byproduct of our emphasis on autonomy over the decades, is also profound. While the emphasis on autonomy was necessary and important, it has separated the individual from a variety of communities. The philosophy surrounding autonomy argues that it is the individual who must evaluate and calculate the various benefits and burdens as they affect his or her life. A strict or strong interpretation of autonomy, then, isolates the individual from communities: one's family, physician, religious community, friends. Consequently, at this critical juncture of our lives, we are left to our own devices.

Religiously and spiritually, this is a disaster

because community is at the heart of religion. It is a source of formation, of inspiration, of values, and a source of personal and familial nourishment at the most profound levels of our lives. A strict interpretation of autonomy privatizes the reality of religion and removes its formative and supportive dimensions from an individual at the moment when these are most needed. Thus, autonomy reduces religion to yet another life style option, which is at the discretion of the individual.

Religious Resources

Religion, unfortunately, solves none of the problems described here. It cannot remove the terror of death; it cannot restore someone from a coma; it cannot make technology do what it does not have the capacity to do; and it cannot necessarily explain why this person has this disease. But religion brings resources to the individual at this most critical time in his or her life.

First, religion provides a community: individuals with whom to associate, to pray and play, and with whom we can make contributions to others in this and other communities. It becomes a social location where we can discover other dimensions of ourselves through service to others, and where we can receive service from others.

A genuine community does not exclude the concept of autonomy, but affirms that the self in isolation typically does not achieve fullness of development. Our deepest sense of self is achieved with and through others. While it is true that we may be the best judge of our needs, a community helps us expand the sense of what our needs may be and of how to achieve them. Thus, we may come to a keener experience of self through our participation in the community. A community also provides a group to accompany us at difficult times, a source of comfort during personal crisis. The reciprocity nature of community assures us that we are not alone in our journey.

Second, religion offers the possibility of hope and some type of transfigured life. It is a structured way through which we try to experience the transcendent in our lives. However we

characterize this — the ground of being, the mysterious, the holy, the other, the divine — what we are trying to experience is a sense of completion. Although finite and limited, our lives reach for a beyond, a transcendent. At its best, religion helps us experience that dimension whether through worship services, prayer, reading, or meditation.

Does this mean religion is a magic fix in our lives, the solution to our problems? Many think this to be the case and become bitter when life remains the same. Religion can, however, provide a grounding for living and especially for dying. Over the past two years I have watched my sister-in-law die of cancer. She was sixty-two, diagnosed in August, and dead in March. A friend, also in his early sixties, was diagnosed with a brain tumor and buried seven weeks later. They were people with deep religious convictions. Both had dark times and struggles in dealing with the reality of their conditions, but they also experienced an acceptance that gave them tranquility and a peace. This was not a passive acceptance or a kind of fatalism, but rather an active choosing of being in a presence beyond them and trusting in the ultimate goodness of that reality.

At its deepest level religion offers us the possibility of a different journey, a journey through our finiteness and limitations to an experience of transcendence. And ultimately the consequence of this experience is a type of peace or acceptance that allows a letting go of the immediate and an openness to another level or dimension of life.

Conclusions

What, then, can we learn from this?

First, community, religious or not, is critical to bear the burden of the terminally ill. The presence of another is critical for a patient's minimal well being. Communities have a responsibility to reach out to those in their fold who are ill and dying. They need to contact the terminally ill, make visits easy to arrange, design hospitals and hospices so that they are not isolating, to impress upon communities the responsibility and need to reach out to members of the community in their time of need.

Second, chaplains need to be part of all hospital staffs. While more common now, it needs high priority. A chaplain can focus on broader needs of patients that are sometimes overlooked in the press of providing medical care. She or he can provide traditional worship opportunities in the chapel and can also offer prayer at the bedside, counseling opportunities, and visits to patients and families. Chaplains can raise issues that others are often reluctant to raise. While a particular patient might not want to discuss religious issues, others may respond to the opportunity and discover new dimensions to their life. The chaplain has the opportunity to make such conversations a possibility and to provide a service to the patient.

Third, we need to develop new religious rituals for the dying. While it is traditional for clergy to pray for the sick, and while many religions have special rituals for the sick and dying, these are often general in nature. While appropriate, they are not specific to the situation. Withdrawal of a life-support system is a critical moment in which a religious ritual is appropriate and beneficial (Shannon and Faso 1985). This process is often traumatic for family; a religious ritual directed to that event can help in several ways. People are conflicted when a decision to withdraw treatment occurs because they need to acknowledge that the treatment is not effective and that the patient, in fact, will die. A ritual brings closure to the attempt to heal and focuses attention on the need to accompany the patient on this last journey. Finally, this ritual permits the community to say farewell to loved ones and to allow the grieving process to begin.

While removal of life support and terminating treatment is common, frequently these decisions

are seen as primarily medical and are carried out as any other medical procedure would be. Marking the event with a religious ritual allows the family to be a more integral part of the process and to experience healing through it. Similar rituals or prayers could be developed, for example, for birth, organ transplantation, cardiac surgery, or discharge from the hospital, each providing a supportive atmosphere in which the reality of the situation is acknowledged and people receive additional resources to process this event.

There are then, various contexts in which people die in America. These contexts add layers of complexity and difficulty to an already emotionally charged situation. Such contexts can be reshaped by the addition of a religious or spiritual dimension. This can bring new meaning to the dying process, can help transform it, and can help the patient experience another dimension to his or her life. Although these opportunities will not resolve all the issues of illness or dying, they can provide patients with the means to see realities of human life from a different vantage point and perhaps offer an unexpected gift of peace at the time of need.

References

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