pirituality pertains to the personal meaning that each of us bestows upon human life and destiny. Often the inherently human drive to create ultimate meaning finds expression in formal religious beliefs and practices, but it may also take shape in less formal philosophies of life and action. For example, the Christian belief in creation provides a meaningful rationale for some environmentalists, while New Age environmental philosophy gives meaning to the efforts of many non-religious activists. The underlying dynamic is the same: The human person, either individually or in community, thirsts for meaning. Spirituality is the human quest to slake our thirst for meaning and motivate informed, purposeful action.

Although the physical, psychological, and social aspects of the dying experience warrant careful consideration, the spiritual dimension is central. Spirituality creates an umbrella of meaning, a context for understanding — or at least coping with — the inevitability of approaching death. As a life is ending, either our own or someone else's, we confront the ultimate meaning of human existence in general, and perhaps more important, we reckon with the meaning of our own individual lives. Spirituality guides us to the core of our being in search of those fundamental values that can shape the experience of death and guide us across the threshold.

The Spiritual Side of Dying

by Laurence J.
O'Connell

Spirituality, then, is not something esoteric; it is our commonplace effort to construct meaning and make our way through life unto death.

The publication in late 1995 of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) has led to renewed and urgent attention to developing new approaches to improving care at the end of life (Support Investigators 1995). The SUPPORT study, funded by The Robert Wood Johnson Foundation, demonstrated that the circumstances of death could not be improved through mere clinical maneuvers that do not tap into the deep, value-laden, lived experience of clinicians, patients, and families. Enhancing the flow of clinically relevant information, a central goal of the SUPPORT study, seems to have done little to penetrate and actualize the profoundly human dimensions of the dying process.

In short, the SUPPORT study, although well motivated and expertly implemented, failed to embrace the fullness of death's complex dynamic. Inattention to spirituality and spiritual distress among patients, families, and practitioners was overlooked. Given the medical orientation of the SUPPORT research agenda, the narrow focus of the enterprise made sense; but, more importantly, it made an important point: establishing a more humane — indeed human — support system for death and dying will demand attention to the fullness of the human person, including the often neglected spiritual dimension.

Everyone struggles to construct a meaningful world view that, in a sense, enfolds them and anchors them in the face of life's fundamental ambiguity. Each of us draws upon our own spirituality for practical guidance as we encounter critical junctures in the journey of life. Death, of course, is the final turn and thus the dying process naturally excites the spiritual sensitivities of everyone involved. To the degree that these sensitivities are acknowledged and actualized the likelihood of a more human and humane death increases greatly. Spiritual inattentiveness in the face of dying and death can, and often does, lead to the sad spectacle of medical technology run amok. The technology literally smothers the person and snuffs out every attempt to construct meaning near the very end of life. Tethered to machines and often in pain, persons in the United States are routinely denied the meaningful death that human dignity requires and we, as a nation of caring citizens, should foster.

Brutalization of the human spirit through aggressive over treatment and/or the selfish self -involvement of those in attendance frequently trammel the wishes and world view of the dying person. Peaceful dying becomes the helpless hostage of an alien spirituality, shaped by battlefield imagery and buttressed by the denial of death as an acceptable medical outcome. This state of affairs underscores a fundamental issue: How can

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we overcome the dehumanizing effects of spiritual inattentiveness and improve the care of dying persons, while at the same time neither minimizing nor abandoning the obvious benefits that modern medicine can offer?

An openness to spirituality is blunted by certain deeply entrenched American values: individualism, commercialism, secularism, and technological utopianism, for example. Each of these values has made positive contributions to the well-being of Americans, but currently they are unleashing negative impulses that affect our understanding of health care generally and our approach to end-of-life care specifically. Health care is considered by many a commodity that can be bought and sold in the market place by those who can afford it. It represents an exchange of technological goods and expertise for profit. The materialistic tenor of large segments of today's health care system militates against the inclusion of the spiritual dimension. One undeniable symptom of this attitude is evidenced in the reductions of pastoral care and social work staffs in many hospitals. These cutbacks should not be attributed to the ill will of administrators. They merely reflect a health care system that is increasingly driven by financial incentives.

Despite the seeming intractability of some cultural barriers, there are emergent signs of hope that signal a willingness to revise values and restructure practice, at least in improving quality of life at the end of life. For example, building upon the learnings from the SUPPORT study, The Robert Wood Johnson Foundation has established a major initiative, *Last Acts: A Strategy for Change*, aimed at creating new approaches to improving care at the end of life. The Foundation has greatly expanded the circle of concerns to be addressed, including explicit attention to religion, spirituality, belief, and the existential needs of dying patients and their families.

There are myriad ways in which spirituality can be addressed with reference to end-of-life care. Two avenues seem particularly promising. First, we can draw upon the resources of traditional spiritual and religious traditions, which themselves represent value-laden repositories within American culture. These traditions harbor the potential to positively counter-balance negative cultural values and to help create a more spiritually receptive environment. Second, we can assist health care providers who are often caught in the middle of conflicting value systems.

Major initiatives directed at religious congregations will heighten awareness and focus an agenda for change. Organized discussions and well-informed preaching on the conflict between current practices and central spiritual and religious values would help congregants recognize the dissonance between what they ought to be seeking and what they are in fact likely to receive near the end of life. Recognizing the source of

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dissonance is the first step in eliminating it. Until we surface, acknowledge, and critique competing values, meaningful changes in our approaches to care at the end of life will elude us. It is important to understand those underlying values that divide us as well as the shared values that might serve as the moral foundation for a new approach. Religious congregations are well suited to promote serious discussion of competing cultural values.

Members of the health care team are no less subject to the influence of cultural pressures than others. Often, they are unfairly expected to serve two or more distinctively different value systems. Although they do manage, almost miraculously, to mediate between vying values — patient care vs. cost containment, for example — their ingenuity does run out. They sometimes find themselves morally conflicted and in need of spiritual relief. They should not be left in the lurch.

Programs should be developed to help providers connect their day-today clinical practice with their own spiritual aspirations. As noted earlier, not everyone embraces religion; but everyone does practice some form of personal spirituality, that is, a preferred method for constructing a meaningful life through reflection and consequent action.

The alienation, fragmentation, and diminishment that dying patients experience extends to caregivers. The chasm that sometimes opens between their clinical practice, on the one hand, and their need for personal meaning, on the other hand, generates anxiety and even depression for some physicians, nurses, and other providers. The result is burnout, which is the practical consequence of spiritual inattention. In short, the thirst for meaning and practical consistency is ignored at one's own peril.

Spirituality, that drive to create meaning and act purposefully, is an essential part of life — and death. "When your soul awakens, your destiny becomes urgent with creativity."

Delving into the spiritual side of life can evoke broader frameworks of meaning that cradle and thus soften death's blunt finality. Quite simply, the spiritual side of dying is an important part of life.

References

O'Donohue, John. 1997. *Anan Cara: A Book of Celtic Wisdom*. New York, NY: Harper Collins Publishers, Inc., 82.

The Support Principal Investigators. 1995. "A Controlled Study to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Treatments (SUPPORT)." *JAMA* 274 (2): 1591-1598.

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