Commentary

Understanding Suffering: What Palliative Medicine Teaches Us

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Hope does not lie in a way out, but in a way through.
—Robert Frost

The ongoing debate about physician-assisted suicide, with its anguished public arguments, is having a salutary side effect. It is forcing the medical profession to be introspective about the manner in which physicians and our systems of health care understand and deal with suffering. Jack Kevorkian's clients have believed that it is necessary to search beyond their own physicians and local health-care milieus for what they perceive to be a solution to their suffering. The most troublesome, disquieting cases have involved people in whom no organic disease was found, either ante mortem or post mortem. Nonetheless, these people perceived that death was preferable to continuing to live in their current condition. When we look beyond, for a moment, the ethical and legal issues raised by Kevorkian's activities, we must admit that organized medicine is learning something about itself. When attempting to know what makes people suffer and understanding the means to alleviate that suffering, medicine frequently misses the point.

Response of Medicine to Suffering.—Many investigators, notably Eric Cassell, have explored suffering and the response of medicine to patients who are suffering. According to Cassell, the success of modern medicine has relied on the combination of disease theory and science. In this system, physicians have come "to believe that to know the disease and its treatment is to know the illness and the treatment of the ill person." The person, of course, is much more than his disease. For Cassell, personhood has multiple dimensions in addition to a body or physical being. Suffering occurs when there is a threat, real or perceived, to the intactness of the person, and all dimensions of the person are susceptible to damage or loss. In this system, many avenues exist by which a person might suffer, only one of which is physical.

Medicine evolved throughout the centuries by concentrating narrowly and deeply on one dimension of personhood—the body. By extension, the implication is that, by knowing the body and disease on a detailed molecular level, physicians know about suffering. Recent efforts to add humanities courses to undergraduate medical education, although laudable, are of limited effectiveness in broadening the physician's perspective. The SUPPORT (Study to Understand Prognoses and Preferences for Outcomes of Care of the Ill and End-of-Life Care) trial amply demonstrated that physician education is insufficient for altering physician behavior.2 In postgraduate education and in clinical practice, patient care responsibilities, financial incentives, and academic prestige still reward technical expertise and high patient volume. Well-meaning physicians find that spending the time necessary to address "whole-person needs" creates economic and professional risk. Thus, physicians continue to focus on the physical aspect. When their patients suffer, physicians seek a physical solution. When more than pain medication is needed, however, physicians have had little else to offer.

Palliative Medicine.—The emerging discipline of palliative medicine may provide a model of "whole-person care" for the rest of the profession, a system in which suffering can be better addressed. Palliative medicine evolved from the hospice movement during the 1960s and 1970s. Although hospice programs in the United States initially developed outside of traditional medicine, palliative medicine has become more mainstream as nurses and physicians embrace its philosophy of whole-person care. Research in palliative medicine has become more scientifically rigorous, particularly in the area of symptom control. Physicians are discovering that the principles of palliative medicine enable them to practice medicine in a manner that is both scientifically sound and sensitive to the needs of the "whole person."

The American Board of Hospice and Palliative Medicine offered its first board examination in the fall of 1996. It described hospice and palliative medicine as follows:

...an interdisciplinary approach to the study and care of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is quality of life. This discipline recognizes the multidimensional nature of suffering, responds with care that addresses all these dimensions, and communicates in a language that conveys mutuality, respect, and interdependence.
**Skills of the Mind.**—The tools of palliative medicine reflect the emphasis on quality of life (QOL) and the multidimensional nature of suffering that necessitate a team approach. The first priority of palliative-care teams is aggressive, meticulous symptom management. Patients entering hospice programs typically have multiple severe symptoms¹ (Table 1). One of the most active areas of palliative-care research is symptom control, and many pharmacologic and nonpharmacologic treatments are available.

In keeping with the multidimensional nature of personhood and suffering, palliative-care teams include (in addition to physicians and nurses) a social worker, chaplain, and lay volunteers. Some of the most important care is provided by nonphysician and nonnurse members of the team.

Another developing trend during the past 20 years is QOL research. QOL research has found a niche in palliative care, in which its contributions to the understanding of nonphysical aspects of personhood and suffering are directly applicable. The multidimensional nature of QOL dovetails well with the whole-person approach of palliative medicine. QOL tools characteristically measure multiple dimensions of QOL, including physical, emotional, social, functional, and spiritual domains. Most clinical research protocols in palliative medicine include QOL as the primary outcome measurement.

QOL research serves a valuable function by lending scientific validity to outcomes that are not easily quantified but are of crucial importance for patient well-being. QOL research has limitations, however. Regardless of the detail or validity of a tool, it is difficult to imagine a questionnaire that could get to the heart of deep human experiences like joy, despair, or transcendence. Assigning a number to a subjective experience is a natural step for science, which, according to Cassell,¹ values "hard" data such as numbers, x-rays, or slides of tissue over "soft," subjective, value-laden patient experience.

**Friendship of the Heart.**—Leaders in palliative medicine have recognized the importance of a reasoned, scientific approach to research in palliative care; however, they have also understood the limitations of the scientific method in dealing with human suffering. Carlos Gomez,² medical director of the palliative care unit at the University of Virginia School of Medicine, believes that "there are problems that are entirely human and existential and are not amenable to quick solution by technology....Much of what we are asking is outside the scope of medicine....sometimes what is needed is to bear witness or to be silent."

Empathy, presence, and nonabandonment require more of the physician as a person than as a scientist. The now-famous quote of the patient to Dame Cicely Saunders, founder of the modern hospice movement, crystallizes the essence of this very human aspect: "I only want what is in your mind and in your heart."

Acknowledgment of the limitations of technology logically leads to an exploration of the qualities needed by a physician who cares for patients who are suffering. Ira Byock,³ current president of the American Academy of Hospice and Palliative Medicine, outlined the responsibilities of physicians:

Our task as clinicians is not to provide ultimate answers. Our task is to manifest ultimate commitment....The ability to stand within and navigate within those cold, murky waters is what we can give to those persons whose suffering is not relieved by our protocols and our potions....Adeptness here has more to do with being able to empty oneself and listen. It seems to require an element of surrender. In addition to our medical knowledge and skills, if we are to be of service in the face of persistent suffering, it seems we must allow ourselves to become a vehicle for a more profound and subtle knowledge. Some would call this God, others intuition.

Byock³ furthered emphasized the role of the physician by stating:

...if our interventions are to have any hope of succeeding, they must also be courageous. Make yourself fierce, break in....When suffering persists, our continued commitment to act for the good of our patient necessitates acting without certainty....While ethical guidelines must be respected, if one's commitment to approaching persistent suffering is subordinated to some allegiance to a detached, professional demeanor, some suffering will, inevitably, remain untouched.

To paraphrase Saunders and Balfour Mount, Eric M. Flanders,⁴ chair of palliative medicine at McGill University, stated that the approach to suffering offered by palliative medicine can be summarized as follows: The dying need the *skills of the mind*, embodied in competent medical care, and the *friendship of the heart*, with its caring, acceptance, vulnerability, and reciprocity. Neither alone is sufficient.

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**Table 1.—Prevalence of Symptoms in 275 Consecutive Patients With Advanced Cancer**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Prevalence (%)</th>
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<tbody>
<tr>
<td>Asthenia</td>
<td>90</td>
</tr>
<tr>
<td>Anorexia</td>
<td>85</td>
</tr>
<tr>
<td>Pain</td>
<td>76</td>
</tr>
<tr>
<td>Nausea</td>
<td>68</td>
</tr>
<tr>
<td>Constipation</td>
<td>65</td>
</tr>
<tr>
<td>Sedation-confusion</td>
<td>60</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>12</td>
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Modified from Bruera.¹ By permission.
**Managed Care and Economic Considerations.**—Paradoxically, health-care consumerism and the increasing penetration of managed care into selected markets will clearly provide the impetus for a change in medicine that, up to now, has been lacking. Institutional “report cards” will include patient satisfaction as a key barometer. Physicians and systems that fulfill the perceived needs of patients and families, even if these are nonphysical, will be rewarded.

A sophisticated, in-depth, and trenchant analysis of health maintenance organizations (HMOs) was recently published by the National Committee for Quality Assurance, the main accrediting body for HMOs. Forty-three of the largest HMOs in America were carefully scrutinized on several measures: complaint ratio, meeting of industry standards, measures of satisfaction, and overall quality monitoring. These measures will more than likely be used by corporate America in selecting health plans for membership. Even ready access to sophisticated interventional technology will leave patients dissatisfied if it is not delivered in the context of a caring environment. Although it is unclear from an analysis of extensive managed-care performances since 1980 that these programs offer a substantial clinical advantage, the HMO is clearly entrenched in the medical landscape and will become a model of practice for the foreseeable future.

As medicine heads into the next millennium, it is painfully obvious that economic considerations are driving many medical practices. The Health Care Finances Administration has now sanctioned a coding mechanism for “comfort care.” This position by the federal government provides additional emphasis for the clinician and related agencies to be aware of not only the physical needs of the patient but also the emotional, psychologic, and spiritual dimension of each person.

The issues of QOL, suffering, and the very meaning of life are no longer abstract concepts to be discussed in the hallowed halls of academia. The recent decision by the Supreme Court to review state-mandated bans on physician-assisted suicide brings this issue clearly to the table of public policy. Palliative medicine is now being uniquely positioned to participate in this dialogue.

**Epilogue.**—What can palliative medicine teach the rest of medicine about suffering? First, excellent and uncompromising symptom control is possible and indispensable. Second, the healing of people who are suffering requires attention to all dimensions of personhood, not just the physical aspects. Third, perhaps most important to physicians, palliative-care professionals have discovered that being an agent of healing for another human at the end of life confers a personal richness that is difficult to find elsewhere in medicine. It is not just the patient who is healed.

**REFERENCES**

5. Gomez C. Re-examining the Dutch experience with physician-assisted suicide. Presented at the 11th International Congress on Care of the Terminally Ill; 1996 Sep 7-11; Montreal, Quebec