SPECIAL ARTICLE

When the Spirit Hurts

An Approach to the Suffering Patient

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Our compassion must stem from a recognition of their suffering.

The Dalai Lama

Suffering, or spiritual pain, receives little attention in medical education, research, or practice.[1] Institutional standards for pain management often address only physical pain,[2] the inadequate treatment of which is widespread and well documented.[3-5] However, suffering is more individualized, more elusive than pain.[6,7] Suffering, like physical pain, may go unrecognized and undertreated even in the best settings[1,3,8] and amidst very compassionate caregivers, simply because of inadequate diagnostic skills and knowledge about the nature of suffering.[7] While we may not be able to alleviate suffering in the same manner or to the same degree as we can physical pain, the simple recognition of suffering in the patient is the first step in a truly holistic approach, allowing the patient to feel the therapeutic power of compassion and begin healing.

No specialty or subspecialty is free from patients who are suffering. Although over 2500 clinical practice guidelines pervade medical practice,[9] none deal with something as germane to the healing arts as the recognition and treatment of suffering. Health care providers often cannot perceive what is a source of severe suffering for patients,[1] and patients with apparently "minor" illnesses or conditions can still be suffering greatly.

WHY IS THE RECOGNITION AND ALLEVIATION OF SUFFERING SO IMPORTANT?

Today, patients may have less family or social support systems than they had previously, so they may increasingly turn to their physician for help in dealing with their suffering. Unfortunately, in a survey of care in 5 countries, US hospitals reported the highest number of problems with comfort and pain management.[10] Being sensitive and open to clues of suffering can also enhance the diagnostic yield of the history and reduce unnecessary diagnostic testing or treatments.[11] Recognizing that a patient is suffering can increase patient rapport, confidence, and compliance. Ultimately, the most effective treatment of the whole person cannot occur unless we address concurrent suffering. And even when there is no cure or treatment, simply acknowledging a patient's suffering can be immensely therapeutic.

From the US Army Medical Department Activity, Heidelberg, Germany.

WHY IS THE ALLEVIATION OF SUFFERING SO CHALLENGING?

Health care professionals have difficulty managing suffering for several reasons. Relieving suffering requires considerable focus and attentiveness, but systemic and individual factors can distract us. Many practitioners are younger and have little personal experience with suffering, a major loss, illness, or the death of a loved one. While firsthand experience is not a prerequisite for working in the caring professions, it can greatly enhance empathy if balanced with professional detachment and self-awareness.[6] Without this experience, empathy toward the suffering of others must be actively taught. At present, little teaching is provided about the care of the whole person or the nature of suffering.[6,7] Nursing education is more likely to include teaching of palliative care,[6] whereas medicine is taught as a science with dispassionate observation of measurable facts arranged into patterns. Objective findings are preferred over subjective findings, and little attention is given

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to what is wrong with the person.[7] The frequent embellishments that patients add during history taking are often disregarded, even though they contain powerful messages about patients' fears and suffering.[6,7] When physicians attend to the body rather than the person, they fail to diagnose suffering. When we disregard messages of suffering, we may also inadvertently diminish the accuracy of the history and lose important diagnostic information.[11]

Health care professionals may subconsciously avoid situations associated with suffering, death, or dying.[6,7] Surprisingly, few colleagues from diverse specialties and many locations agreed to help with a performance improvement project involving an anonymous survey exploring patients' perspective of suffering. Was this just a simple lack of curiosity amidst a backdrop of time constraints and other more urgent administrative requirements? Or were they perhaps avoiding the issue? Perhaps another subtle form of avoidance is reflected in the fact that "suffering" is not routinely listed as a potential complication on patient consent forms. Given that medical treatment itself often results in suffering,[1,7] perhaps it should be. Patients expect that pain, for most procedures or operations, can be adequately controlled, but that is not necessarily the same expectation they have with suffering. Most individuals would not refuse a recommended treatment or procedure because it was painful, but they might decline a procedure or treatment, no matter how highly recommended, if it were expected to increase suffering.

HOW CAN WE IMPROVE OUR ABILITY TO RECOGNIZE SUFFERING?

Patients suffer not only from physical pain or other aspects of their disease, but also from its treatment.[1] In an unpublished multinational survey (2003; data available from the author on request), physical pain was listed among the least frequent causes of suffering. In a published report, those patients with amyotrophic lateral sclerosis who were interested in assisted suicide were not seeking to end their lives because of pain but because of distress at being a burden to others or because of suffering from some discomfort other than pain.[12] Nausea, depression, surgical disfigurement, or loss of hair or function can cause as much suffering as physical pain. Severity does not predict distress, and conditions in which the disfiguration from either the disease or its treatment are relatively minor can be very disturbing to some patients.[13] Since we cannot often accurately anticipate the cause or degree of suffering in our patients, we must ask them. Asking can often lead to unexpected or enlightening replies. The following response is from a patient with Parkinson disease:

> You don't know how bad it is when your body won't do what you want it to do. It took me 10 minutes just to roll over in bed because I had to think about every little movement.

Openness and frankness are best: "Are you suffering?" "What is the worst thing about all this for you, for your family?" "I know you have pain, but are there things that are even worse than the pain?" "Are you frightened by all this?" "What exactly are you frightened of?" "What are you afraid is going to happen?" The questions, slightly vague and always open ended, imply that patients have permission to talk about things that perhaps no one wanted to hear about before. Once asked, patients need sufficient time to answer. In the beginning, physicians may find these to be very uncomfortable conversations, feeling helpless in the face of the patients' answers. Such open-ended questions invite a variety of answers, some of which might be daunting to even the most prepared physician. But just the factor of actively listening is often very beneficial for the patient and also rewarding for the physician, certainly compensating for any time or discomfort that such inquiry may have provoked.[7,14]

Asking patients directly about their suffering is important for another reason: it may be the only means of identifying and rectifying system problems responsible for increasing suffering during a hospitalization. Medical record review or administrative data might not indicate that a particular hospitalization was chaotic or caused a great deal of suffering due to system failures.[5] Patients are the only source of information about whether they were treated with dignity and respect. Examining a hospitalization through the patents' eyes—by direct, open-ended questioning—is often the only way to reveal important information about a hospital system's communication, education, and pain-management processes.[5] In addition to direct open-ended questioning, health-related quality-of-life assessments have been shown to facilitate communication and increase awareness of difficult problems in patients receiving palliative care.[15]

Our reliance on formalized assessments or algorithmic approaches to medicine, although beneficial, has the disadvantage in that it may occasionally eclipse the art of medicine.[16] At most, the "art" is a thin layer of kindness that can soften our passage through the world of medical technology. Much of the public views physicians as mere technicians, who are insensitive to the human condition.[7,16,17] Some residency programs have instituted psychosocial teaching rounds in which a psychiatrist helps house staff understand the emotional aspects of illness and suffering.

HOW CAN WE IMPROVE OUR ABILITY TO RELIEVE SUFFERING?

Just as surgeons train their hands or executives hone their management style, all physicians must sharpen their skills for alleviating suffering by focusing their minds and hearts on the nature of suffering. Searching MEDLINE and the other biomedical databases, even with broad subject headings such as "suffering" or "patient suffering," yields few helpful citations. So some physicians have turned to classical and contemporary literature, allowing prose and poetry to lead them deeper into the human condition and the nature of suffering, and in doing so emerged not only as better healers, but also as famous writers. William Carlos Williams, Anton Chekhov, John Keats, William Osler, Arthur Conan Doyle, Johann von Goethe, and W. Somerset Maugham were just a few in

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An Annotated Bibliography of Suffering

Books Dealing With Suffering		
Title	**Author(s) or Editor(s)/Publisher**	**Highlights**
The Physician in Literature	Norman Cousins, ed/Saunders Press (Philadelphia, Pa)	Anthology of poems, essays, and short stories by famous authors and physicians exploring the relationships between writer and patient and physician and writer; divided into 12 sections—especially relevant are "The Role of the Physician," "The Patient," "Madness," "Dying," and "An Enduring Tradition." (477 pp)
On Doctoring	Richard Reynolds and John Stone, eds/Simon & Schuster Inc (New York, NY)	Collection of poems, essays, and stories from famous writers and physicians on the themes of medicine as a human endeavor and what it is like to be sick, to be cured, to lose, or to triumph over illness. (428 pp)
Hello Darkness	L. E. Sissman/Little, Brown & Co Inc (Boston, Mass)	A collection of 134 poems dealing with ordinary and extraordinary experiences of sickness and dying, especially suffering, in hospitals; many are inspired by the author's terminal illness. (294 pp)
Otherwise	Jane Kenyon/Graywolf Press (St Paul, Minn)	A collection of poems that express the author's struggle with depression, the death of her loves ones, the discomfort and degradation of undergoing repetitive diagnostic tests, and her initial emotions on being told she has cancer. The title poem poignantly describes the impact of realizing that slowly she will lose the ability to do the simple things that most take for granted. In "The Sick Wife," she poignantly describes suffering from being too weak to button her blouse. (230 pp)
The Gift Nobody Wants	Paul Brand and Philip Yancy/Harper Collins Publications Inc (New York)	An in depth, semibiographical look at the physiology, etiology, and emotional-spiritual aspects of illness that involve the dimunition or inability to feel pain and the immense suffering that result from being painless. A valuable read that could help those in chronic pain better cope and an excellent resource for clinicians who treat chronic pain. (340 pp)
Lessons From the School of Suffering	Rev Jim Willig/St Anthony Messenger Press (Cincinnati, Ohio)	A candid and intimate autobiographical account of his suffering, offering lessons in how to embrace the unavoidable, and making clear the distinction between spiritual healing and physical care. (100 pp)
Squares and Courtyards	Marilyn Hacker/WW Norton & Co (New York)	Collection of poems confronting person suffering from undergoing chemotherapy, losing friends, and dealing with AIDS. Particularly relevant words are "Grief," "Wednesday ID Clinic," "Scars on Paper," "Twelfth Floor West," and the title piece. (107 pp)
Blood and Bones	Angela Belli and Jack Coulehan/University of Iowa Press (Iowa City)	Anthology of 100 poems by physicians, recording instances of pain, grief, recovery, joy, and humor in the setting of caregivers and patients from both the caregivers and patients perspective. Highly recommended. (160 pp)
Articulations: The Body and Illness in Poetry	Jon Mukand/University of Iowa Press (Iowa City)	The second volume of inspiring poems (*Sutured Words* is the first) embracing the mental and emotional complexity of healing, illness, death, and all human dimensions of suffering. As stated by the *New England Journal of Medicine*: "for any physician who believes that participation in the mainstream of emotional expression is an integral part of professional life." (426 pp)
Savage Beauty	Nancy Milford/Random House (New York)	Biography of the poet Edna St Vincent Millay. Several chapters offer insight into suffering, especially that due to addiction (chapters 9 and 10). Chapter 10 shows how treating physical pain alone is not enough and how one continues to suffer despite adequate pain management. She laconically and insightfully summarizes her physician's inattentiveness to her suffering, telling him "you are far too medical." (576 pp)
Hymn to God, My God, in My Sickness	"John Donne" in *Genius* by Harold Bloom/Warner Books (New York)	In contrast to the Millay experience, Donne describes how, because of his physician's love and holistic focus, his dying moments are transformed into ones of peace and contentment. (pages 257-267.)
The Lost Art of Healing	Bernard Lown/Houghton Mifflin Co (Boston)	Promoting the style of medicine as described by the 16th-century German physician Paracelsus who said that the basic qualifications of a physician included "intuition which is necessary to understand the patient, his body, his disease. He must have the feel and touch which made it possible for him to be in sympathetic communication with the patient's spirit." (344 pp)

Web Sites Dealing With Suffering

The Yale Journal for Humanities in Medicine
http://info.med.yale.edu/intmed/hummed/yjhm/spirit/suffering/sufferingintro.htm
http://info.med.yale.edu/intmed/hummed/yjhm/spirit/suffering/gyuan1.htm
http://info.med.yale.edu/intmed/hummed/yjhm/spirit/suffering/jkeenan1.htm

Thoughts on Suffering
http://jmahoney.com/SUFFERING.html

The Aeschi Working Group
http://www.aeschiconference.unibe.ch

whom medicine and literature cohabited in symbiotic concord, enriching them both as writers and as physicians. Like many suffering patients, they found in literature a vast network of healing symbols (**Table**).

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Shelley attributed a moral dimension to poetry, because it enabled poets to connect with others. Some works that are especially relevant because they specifically describe the circumstances and emotions of patients suffering from their illness or treatment are highlighted in the Table.

We can improve the alleviation of suffering from both an individual and a systems standpoint. With either approach, seemingly small or insignificant changes can have profound impact. On an individual basis, simply knowing or believing that suffering is treatable helps tremendously.[18] Otherwise, although our compassion may be strong, it is likely to have a quality of hopelessness, even despair.[18] However, even in the face of apparent hopelessness, the smallest gesture such as touching the patient or family member or not being afraid to show emotion or sensitivity can be therapeutic.

When the veterinarian kissed my gravely ill dog's head, it was a compassionate act. Even though there was no cure, no diagnosis, and nothing more this clinician could do, my suffering was somehow reduced (Caroline Lesho, personal communication, January 25, 2003).

Sometimes we forget that those who may be suffering the most are not ones who are ill or being treated, but rather the family or loved ones. It is just as important to carefully explain the disease and its treatment to them as it is to the patient. This alleviates some of the suffering that comes from "not knowing" how much their loved one is suffering, especially noncommunicative loved ones.

"Why did this happen to me?" Listening and facilitating a patient's exploration of this common question can also reduce suffering. Depression, a frequent cause of suffering,[1,6,7] often accompanies many illnesses, but frequently goes unrecognized and undertreated.[19] Improving our ability to recognize and treat depression is another step toward reducing the burden of suffering.

From the systems standpoint, we can adopt the recent Institute of Medicine's patient-centered approach to hospitalizations, which emphasizes respect for patients' values and preferences, coordination and integration of care, communication and education, physical comfort, emotional support, and involvement of family and friends.[20]

Another focus could be improving access to care—especially for managed care, Medicare/Medicaid, or uninsured patients. With worries or fears of a real or presumed illness, some suffer because they are unable to get a timely appointment. With a policy of "open access," adopted by several facilities, patients are seen on the same day that they call to schedule an appointment. Based on patient surveys, satisfaction with open access is high. Some people suffer as they wait for the results of laboratory tests or radiography, which, if normal, may assume low priority on the telephone-consult callback list, causing them to suffer longer. Faster call-backs or automated e-mail services that allow the provider to immediately forward results or interpretations to the patient can help reduce unnecessary worry or suffering. Redesigning work processes and redefining staff roles that decentralize decision making, use flexibility, and encourage innovation can reduce suffering during a hospitalization.[5]

The debate on which indicators are best suited for the evaluation of the quality of medical care continues, as does the debate about which aspects of the current health care system are most in need of reform. The one thing that everyone seems to agree on is that, ultimately, patients will judge quality by whether their physician is caring and compassionate.[21] The treatment of suffering offers us perhaps the greatest opportunity for spiritual and professional growth. It begins with compassion.

Accepted for publication August 1, 2003.

The views expressed in this article are those of the author and do not reflect the official policy or position of the Department of Defense or the US government.

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