END-OF-LIFE
and
PALLIATIVE CARE

Contents

BOOK REVIEWS

GUEST AUTHOR INFORMATION

Sheldon M. Feldman, MD is Chief of Breast Surgery and Chief of the Louis Venet Comprehensive Breast Service at Beth Israel Medical Center in New York City.
SFeldman@chpnet.org

Marcia Levetown, MD is a pediatric intensivist whose interests evolved to communication, ethics, palliative and family-centered care for patients of all ages. She is an independent consultant to healthcare providers, institutions and layperson groups and lives in Houston, TX.
mlevetown@earthlink.net

Controlling Pain at the End of Life

By Marcia Levetown, MD

The prevention and relief of suffering is one of the most rewarding aspects of healthcare practice. Patients and families are enormously grateful and the providers have achieved one of the most long-standing and revered goals of medicine. Yet, pain control is rare. How can pain management, particularly for the terminally ill and imminently dying, be more effective? Correction of important knowledge deficits, misperceptions and attitudes are critical first steps, beginning with…

Believing the patient: The gold standard for pain assessment is the patient's self-report. Facial expression, vital signs, diagnostic tests and other "objective measures" *do not* accurately assess pain. Why? Pain perception is based on complex interactions of electrical impulses, neurotransmitters, endogenous endorphins, pharmacogenetics, meaning of pain, degree of somatic hypervigilance, past relief of pain (or not) in healthcare settings, feeling respected or abandoned, whether the patient is rested, has fear, anxiety, or depression. An MRI or a vital sign cannot begin to capture this amalgam of data. *Until we give our patients tools to communicate their degree of pain and believe their report, we cannot hope to help*. Effective pharmacologic management will come more readily when an accurate understanding of the following concepts becomes more common:

Dependence: a physical phenomenon associated with chronic administration of an agent, leading to a predictable complex of symptoms when the drug is stopped, the dose is markedly decreased, or the drug is reversed – common with anti-convulsants, steroids, benzodiazepines, opioids, other agents.

Tolerance: a physical phenomenon of need for increased doses over time to achieve the desired clinical outcome; due to receptor down-regulation, common with parenteral administration of short-acting opiods. The need for increased dosages among the terminally ill, especially of orally administered, long-acting opiods, most often represents disease progression, rather than tolerance.

Addiction: a biopsychosocial phenomenon indicated by use of a substance despite self-harm, often associated with a compulsion to obtain the substance regardless of consequences. Dose, duration of treatment and withdrawal are IRRELEVANT to the diagnosis. Attempts to "wean" the patient with good pain control in the absence of adverse side effects are misguided.

Controlling Pain at the End-of-Life: It is well-documented that patients with life-threatening conditions have a high incidence of significant pain, regardless of underlying diagnosis. Aggressive pharmacologic therapy as well as physical measures, such as repositioning, massage, heat and cold, etc. are often key to pain control. Effective pain control is achievable for the vast majority of patients.

Distinguishing neuropathic pain from nociceptive pain is also critical to effective treatment. Neuropathic pain, reflecting injury to nerves, is reported as shock-like, electric, buzzing, burning, gnawing ache, like an ice-pick, or is exquisitely sensitive to light touch. It is best treated with tricyclic anti-depressants and anti-convulsants, but these take a long time (weeks) to get to a therapeutic level. Nociceptive pain, reflecting injury to soft-tissues and bones, is best treated with NSAIDs, aectaminophen and opioids. ALL severe pain should be treated with opioids due to the fact that they can be titrated rapidly. Pure opioids have NO MAXIMUM dose. The "correct" dose is determined by rapid titration based on the patient's report of pain severity, route of administration (parenteral is faster), vital signs, patient's level of consciousness and report of adverse effects.

Carefully titrated pain control is NOT tantamount to assisted suicide or euthanasia. Euthanasia is the purposeful killing of the patient – recognized by administering a large dose of potassium, or a dose of medication not supported by the patient's response to previous doses. While doubling the dose of opioid for a patient in agony IS justified, giving 5-10 times the previous dose in one step, or escalating doses regardless of patient response is suspect. If the patient happens to die during treatment, it is important to remember that the patient is terminally ill and expected to die. If he or she is getting medication frequently, it is likely that the patient will die near the time of a dose. The medication is unrelated to the cause of death.

Rather than focusing on fears of liability, we should focus on the epidemic of undertreated pain, particularly for the terminally ill. Be different. Be the doctor or nurse you want to have when you are dying. Your patients, their families and you will never forget your heroism.

BOOK REVIEWS

Communication Skills That Heal: a practical approach to a new professionalism in medicine

By Barry Bub, MD • Radcliffe Publishing • 157 pgs. • $39.95

Reviewed by Sheldon M. Feldman, MD

Dr. Bub well defines the growing challenges involved in providing high quality care to patients today. Despite significant scientific and technological advances, both patients and health care workers frequently experience extreme dissatisfaction. The frenetic pace of modern living – including many who strive to be more efficient through multitasking and aids such as laptops and dictaphones – can significantly obstruct human connection. As a medical student I was taught that 90% of diagnoses can be made by taking a careful history. This skill has been largely lost by many younger colleagues who often rely primarily on lab tests and scans. The value of really " listening" to our patients is stressed.

This book provides an excellent guide for working toward a new health care paradigm with a hopeful and visionary tone. It stresses humanism, compassion and reclaiming healing modalities. This work is concise and well written in a clinical context, providing specific practice points for immediate use. Common misconceptions about good communication being too time consuming and frustrations about not knowing what to say are clearly dispelled. Better communication rather than longer communication is highlighted. The art of careful, mindful listening is well illuminated. Dr. Bub clearly shows how very often saying less can be much more. Words can be very powerful and once spoken cannot be erased. Words can easily wound rather than heal. Focusing techniques to avoid careless language are described.

The context for healing and the importance of self-care are stressed. We cannot help others if our own emotional state is tenuous. This book illustrates how embracing healing principles can greatly improve our daily experience both in the health care environment and in the world at large. Chapters providing useful information about learning to detect depression, trauma, shame and suffering are very helpful. The tools and techniques of metaphor, simile, rituals and setting boundaries are well elaborated. Brief insights into Gestalt psychotherapy are presented. In spite of having been a student of physician/patient communication skills for many years my consciousness in this area is significantly expanded by this book. It will become required reading for our medical students and residents. Dr. Bub has made an important contribution through this important work.

The Nature of Suffering AND THE GOALS OF MEDICINE, 2nd ed.

By Eric J. Cassell • Oxford University Press • $24.95

Few would deny that medicine's focus on curing, or mitigating, diseases has been both important and often successful. Certainly not Dr. Cassell. Yet in his book, he presents a compelling case that the primacy given to the medical model of care has not served patients well. Indeed, his very first words are:

> *"The test of a system of medicine should be its adequacy in the face of suffering; this book starts from the premise that modern medicine has failed that test."* (pg. v)

The reason, he states, is because suffering is a condition experienced by the person that is the patient and medicine's love affair with the idea of science and technology has led too many practitioners to lose touch with not only the person of the patient, but the person of themselves – thus losing the ability to help patients by using their subjective insights. One reason for this is, what he calls, a "law of soft facts":

> *"'Harder' facts drive 'softer' facts into hiding. Numerical data puts in doubt evidence from the eyes and ears, which puts in doubt evidence from the other senses..."* (pg. 291)

While it's true that over the last 30 years a greater, and ever-increasing, emphasis is being placed on the need to focus on the *sick person* as opposed to the *disease,* widespread change is far from being achieved. Cassell attributes this to a number of things, not the least of which are:

> *"The solid intellectual foundation has not yet been constructed, the ideas on which the change is based have only been articulated by a minority and the lessons that must be learned before the transformation is routinized have not yet been taught."* (pg.vi)

In making his case for a model of care centered on the person, rather than the disease, Cassell offers what might be considered an intellectual foundation for this change. Through a thorough and meticulously detailed analysis (illustrated by numerous examples) he looks at the history of theories of medicine; era-related concepts of the ideal physician; the nature of suffering and, because the person and suffering are inseparable, concepts of personhood. Other topics covered include the doctor-patient relationship and its role in the ability of doctors to heal patients as well as ways of understanding diseases and treating the persons who have them. This second edition ends with three new chapters entitled "Mind and Body," "The Illness Called Dying," and "Pain and Suffering." As in the first edition, the book is capped with an epilogue that offers practical suggestions for the care of suffering patients.

Long before the end of this book, readers will likely see the merit of his position and appreciate that the primary goal of medicine, above all other goals, should be the relief of suffering – something that is possible even when cure of the disease is not. (Hence the distinction between curing and healing.) Just imagine what that would do for patients. Imagine what it would do for physicians and other practitioners to be able to still help in a meaningful way even when they are powerless to cure!