Pain, Suffering, and Meaning

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Every doctor who treats patients will confront their pain and suffering. Yet for each individual patient the experience of pain will be private and largely unique. This creates difficulty not only for the clinician but for anyone who tries to grasp the meaning of someone else’s pain.

The sensory component of pain, the neuronal capacity to localize and identify noxious stimuli, is largely consistent both within an individual and between populations. But the meaning of pain becomes much more than the ability simply to localize or discern it. For the affective component of pain—the subjective sense of suffering that accompanies its perception—is multifactorial.

Myriad factors underlie our ability to conceptualize our own pain, or to comprehend that of another: the meaning of the pain within one’s larger life context, the intensity and location of the pain, the particular illness associated with the pain, the rituals of medicine around pain, and the social understanding of suffering. The pain that results from this multiplicity of factors is uniquely defined for each individual; pain becomes framed in the clinical encounter by the interplay between the physician’s gaze into the patient and the patient’s gaze into himself or herself.

This exercise of framing is at the center of every patient-physician encounter, but most particularly so for pain. For pain is not an objective and visible clinical finding in the manner of a fractured femur or purulent sputum. Rather, pain is a perception communicated through both language and nonverbal behaviors such as tears or agitation. As such, pain is intrinsically subjective and inaccessible, “that which cannot be denied, and that which cannot be confirmed.”

This intangibility contributes to misunderstanding and undertreatment of pain in the clinical setting. As discussed by Kathleen Foley in this issue, pain remains a serious public health problem. Many patients are inadequately palliated, especially at the end of life. This need not be so. Janet Abraham describes how we can make palliative care itself a goal of medicine. Even when cure of the underlying disease is not possible, there is still much we can do to relieve physical and psychosocial suffering. Jane Loike recounts that many patients seek pain relief from complementary therapies. Often they feel that these methods offer a holistic approach that is lacking in the traditional allopathic model.

As we grapple for solutions to these problems within our current clinical context, we might do well to realize that none of these experiences are entirely new. Schuyler Henderson describes the expressions and definitions of pain as a function of not only personal but social, cultural, and historical influences as well.

To treat pain adequately therefore requires not just that we understand its pathophysiology, solicit patient reporting, and follow practice guidelines, but that we also reflect on its meanings and thoughtfully incorporate them into our clinical interactions. We hope that this issue of MSJAMA will encourage further thought about current issues in pain management and its significance within the clinical encounter.

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Dismantling the Barriers: Providing Palliative and Pain Care

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In 1997, the Institute of Medicine (IOM) published a report, Approaching Death, that called for the need to improve care of patients at the end of life. The IOM report identified serious deficiencies in the current provision of palliative care in the United States. Among its 7 recommendations, health care professionals were asked to commit themselves to use existing knowledge to reduce pain and manage symptoms in patients facing death. The report also recommended that medical training programs educate practitioners in the care of dying patients.

For patients whose disease is not responsive to curative therapies, palliative care offers pain control, symptom management, and psychological and existential support to maximize patients’ quality of life. Historically, cancer has served as the model disease in the development of hospice and palliative care services, but importantly, the IOM report calls for the expansion of such services to patients with noncancerous chronic illnesses.

Providing compassionate and competent care to dying patients and families is an enormous challenge for the medical profession. Major attitudinal, behavioral, educational, and institutional barriers have been described that prevent physicians from delivering and patients from receiving the desired humane and compassionate treatment. Pain is one of the most common complaints of patients seeking medical attention. Among the general population surveyed in 1997, 72% feared dying in pain. In an earlier survey of cancer patients, 57% endorsed the statement that a painful death can be expected with cancer; 69% reported that they would consider suicide if their pain was not adequately treated.

Prevalence studies reveal that one third of adult and pediatric cancer patients in active therapy and two thirds of those with advanced disease require analgesic drugs. Studies from the World Health Organization Cancer and Palliative Care Unit show that 4.5 million patients from developing and industrialized countries die each year in uncontrolled pain.

In a landmark study of 1308 oncology patients, 56% reported moderate to severe pain, and 72% of physicians expressed their lack of knowledge concerning pain management. Pain is also prominent in seriously ill patients with noncancer diagnoses; moderate to severe pain has been identified as a major symptom in 50% of seriously ill patients who were conscious during the last 3 days of life. These and other data support the concept that pain is a serious public health problem.

Impediments to adequate pain treatment include health care providers’ fear of inducing physical or psychological addiction, misconceptions about pain tolerance, and assessment biases. A strict drug regulatory environment that closely monitors physicians’ prescribing practices further contributes to patients’ undertreatment. Major medical and nursing textbooks devote a few pages to current pain and symptom control guidelines. This inadequacy has been most evident in the care of dying patients in cases where physicians’ ignorance of the proper use of opioids has led to needless suffering. The recent Supreme Court decision against a constitutional right to physician-assisted suicide endorsed the need for pain control and palliative care. More importantly, it supported the aggressive use of opioids to manage symptoms as distinct from physician-assisted suicide.

Advances in pain research have redefined our understanding of tolerance and neuropathic pain, offering new therapies to maximize pain relief and minimize side effects. Protocols, such as the WHO Three Step Analgesic Ladder, provide detailed methods to facilitate pain relief for patients. These efforts, coupled with the IOM’s call to action, are signs that improving pain and palliative care is becoming a priority for medicine. Medical students can participate in curriculum electives that incorporate didactic and experiential learning in pain management and palliative care. Increased attention to pain and palliative care education by each medical school is critical if we are to reduce the barriers to patient undertreatment that education, clinical experience, and role modeling can readily change.

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WHEN ONE OF OUR PATIENTS HAS AN INCURABLE ILLNESS, we physicians must expand our focus of care beyond the disease to encompass all dimensions of the patient’s distress. That is when we begin to deliver palliative care. The World Health Organization defines palliative care as the “active, total care of patients whose disease is not responsive to curative treatment” and notes in a statement that “control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount.” Consider the case of Mr Joseph Taylor, a 71-year-old man with non–small–cell lung cancer who developed a spinal cord compression manifested by severe back pain. Beyond treating this problem, the clinician interested in palliative care will discover his goals and values, identify sources of suffering, and work with him to find the best solutions.

The first opportunity to practice palliative care will be in telling Mr Taylor and his family the diagnosis. No matter how sensitively you break this news, all of you are likely to feel sad. To the degree that you will have succeeded in establishing a valuable relationship, however, the Taylors will look to you for information and support. Buckman suggests 6 steps to minimize the distress of this conversation. First, make yourself, Mr Taylor, and his family comfortable. Second, determine what he knows, not just what he was told. Third, determine what he wants to know. Fourth, disclose the news, in small chunks and in words he will understand. Fifth, listen to his reactions. If he is angry, realize that he is not angry at you. Sixth, review the next steps. If you know what the plan is going to be, tell him. If not, schedule another meeting. Ask for questions (there rarely are any) and invite him to write down questions for the next meeting.

Palliative and Hospice Care
Further staging indicates continued progression of Mr Taylor’s cancer. His physician plans no further chemotherapy but does not tell him that she has nothing more to offer. She discusses both experimental chemotherapy and hospice options with Mr Taylor and his family, offering him not hope of cure but rather the possibility that he will have the time and strength to accomplish the tasks that are important to him. Mr Taylor enrolls in hospice. Hospice seeks neither to prolong life nor to hasten death, but to enhance the quality of remaining life. To be appropriate for hospice care, patients must be terminally ill with a prognosis of 6 months or less. They do not need to be homebound or have a do-not-resuscitate order. For patients at home or in nursing homes, hospices provide nurses, social workers, chaplains, volunteers, home health aides, consultants, medications, equipment, supplies, oxygen, and bereavement care.

Inpatient stays and care in a nursing home, designed to provide a respite for caregivers, are often included.

Fears and Misconceptions About Opioids
Mr Taylor’s pain was well controlled in the hospital, but a month after discharge the pain intensifies. Mr Taylor refuses the opioids suggested by his physician. Patients like Mr Taylor harbor several concerns about opioids that they rarely mention. Common fears include addiction, social isolation from friends, oversedation, and the lost chance to relieve more severe pain by taking opioids later. Through the hospice chaplain Mr Taylor discovers that attending church is a goal strong enough to overcome his fears about opioids. His pain diminishes, and he returns to attending Sunday services.

The Team Approach
Regular discussions among the nurse, social worker, chaplain, and the patient’s physician are needed to address and relieve most of the sources of physical, spiritual, psychological, and social or financial distress that patients and caregivers experience. Extensive information about the role of the team and the practice of palliative and end-of-life care can be found in textbooks, handbooks, and a case-based palliative care manual.

Final Thoughts
Over the next 2 months, Mr Taylor’s pain is well controlled with dexamethasone and an increase in opioids and laxatives. Hospice volunteers help him put his stamp collection in order and finish a cradle for an expected grandchild. His physician’s biweekly phone calls have offered much support, and the hospice social worker and chaplain have helped Mr Taylor’s family begin to accept their impending loss. Four months after you first met him, Mr Taylor dies peacefully in his sleep.

Mr Taylor relied on his physician and nurse to control the pain from bone and spinal cord lesions, but he faced multifaceted distress during his terminal illness. Interdisciplinary teams can address and relieve this distress and in so doing, provide physicians with significant personal and professional satisfaction.

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NO OTHER PHYSICAL EXPERIENCE IS AS HEAVILY IMBUED WITH meaning as pain. The idea that pain is simply the result of an internal physical condition is relatively recent. For many philosophers and cultures, pain has been seen as having an external source such as “God’s arrows.” With this externalizing of pain comes the understanding of pain as meaningful in a social and moral context. The Biblical story of Genesis depicts the introduction of pain and suffering in the human experience as a divine punishment for transgression, and this Judeo-Christian ethos has permeated the West’s understanding of pain.

Throughout literary history, representations of pain have been based on the doctrine of punishment. At the center of Dante’s hell, the monstrous figure of Lucifer torments the 3 men who betrayed their lords: Cassius, Brutus, and Judas Iscariot. In Paradise Lost, Milton describes the “doleful shades” of Hell, relishing the agony of the fallen angels after their violent subordination. In lurid detail, he describes their “torture without end.” Both Dante and Milton carefully emphasize that the pain is permanent, because it is necessary to differentiate punitive pain from the moral cleansing associated with transitory pain. The sacrifice of Jesus on the cross, the ascetic starvation of Siddhartha, and the religious sects that self-flagellate on holy days all manifest the use of pain for purification, purging transgression through temporary painful ablutions. And yet, striving to construct any consistent parallel between morality and pain ultimately must be answered with Hamlet’s bitter question, “Use every man after his desert, and who shall scape whipping?” Despite the ancient association of pain with a person’s moral character and social behavior, it is only in literary and theological texts that such an association is precise.

The notion that pain results from transgression is not solely relegated to the graphic imaginations of writers. One need look no further than certain recent retroviral assertions that AIDS is God’s way of punishing homosexuals to see that for many today, physical suffering is not detached from perceived spiritual health. The consequences of such assertions for those who suffer are significant, both in the individual’s solitary struggle to come to terms with suffering and as they might affect those making health policy.

Because of differing moral and narrative traditions, cultures ascribe meaning to pain in different ways. There have been numerous attempts to discern the extent to which the experience of pain differs among ethnic and national groups. Although some researchers have managed to produce statistically significant data that suggest culturally affiliated influences on the perception and response to experimental, acute, and chronic pain, the confounding factors, often based on differences in expressing pain, usually make any distinctions untenable. Just as the relationship between morality and pain cannot be clearly identified, so too the correlation between physiology and the experience of pain remains elusive.

More pertinent to immediate concerns is the way physicians respond to people in pain based on ethnicity. In an Israeli study, Jewish doctors and midwives assessed the pain (“exhibited pain”) of 225 Jewish and 192 Bedouin parturients, who also assessed their own pain (“self-reported pain”) during delivery. The Jewish and Bedouin women evaluated their pain equivalently, but the doctors and midwives reported less pain in the Bedouin women. We may not be able to explain cultural differences in pain, but we nevertheless perceive such differences.

Medical research has provided us with a rich understanding of the mechanisms of pain, but the physiology of nerves and the anatomy of dermatomes cannot describe the experience of being in pain. Pain is one of the very few experiences that every person will have, and yet it is intensely private. When Virginia Woolf writes that the “merest schoolgirl when she falls in love has Shakespeare or Keats to speak her mind for her, but let a sufferer try to describe a pain in his head to a doctor and language runs dry,” she is pointing to that intrinsic difficulty of conveying to another the personal experience of pain.

In asking about pain, the physician attempts to interpret it as a message coding a pathological process, reading the pain in its relationship to a problem in the body’s functioning that can then be addressed. Not only is this limited by the painless nature of many pathological processes (such as the stealthy streaking of arteries with fatty deposits), but more importantly, the physician will never be able to empathize with his or her patient without trying to understand how that person is experiencing pain.

While the investigation of pain as a physiologic phenomenon is important, pain cannot be reduced to physiology any more than it can be neatly explained by a social or moral paradigm. The difficulty in talking about and understanding another person’s pain stems from its complicated origin in both realms, as a function of our bodies and of our identities.

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Pain and its complications are common problems for physicians, clinicians, and patients. Of the 17 million new cases of cancer reported worldwide each year, 56% of patients indicated having moderate to severe pain 50% of the time, 81% had greater than 2 complaints of pain, and 34% had greater than 3 complaints of pain. Many patients, hopeful of a cure or palliation of their pain, turn to alternative practitioners. From 30% to 70% of patients use alternative or complementary therapies, and while 57% of physicians report a willingness to refer patients for complementary therapies, only 28% of physicians had actually done so.

In its definition of pain, the International Association for the Study of Pain includes actual or potential tissue damage as well as the emotional experience of pain. Understanding the multifaceted experience of pain becomes important in treatment. To mitigate their suffering, patients may turn to complementary and alternative therapies to reduce feelings of stress, anxiety, nervousness, agitation, despondency, lack of motivation, lack of enjoyment, and lethargy.

During medical education, physicians generally are taught that the tools of their trade include pharmacotherapy, surgery, psychotherapy, and physical therapy. Yet other modalities exist for alleviating pain, and physicians can better participate in pain management by learning about the efficacy of complementary therapies and when and where to apply them (TABLE).

The Allopathic Physician’s Approach
In the standard approach to disease the physician must understand the neurophysiology and neuroanatomy of pain. A vocabulary of descriptors must be part of the physician’s armamentarium. A working knowledge of the syndromes associated with various presentations of pain is essential when the physician is obtaining the patient’s history, collecting data, and performing the physical examination. Additional factors help determine what, if any, complementary treatments might help the patient in a given setting when synthesizing an assessment. Those with acute pain need disease treatment and enough symptom relief to tolerate the workup and therapy. Those with malignant or chronic nonmalignant pain need symptom relief that allows optimal physical and mental function and, if death is unavoidable, allows the patient to die relatively free of pain.

Acupuncture
Acupuncture, which originated in China during the Xia dynasty (2140-1711 BC), is based on the concept that the continuous flow of chi, “life energy,” is vital to one’s health. Acupuncture treatments aim to improve health by inserting hair-thin needles into specific points on the body that are thought to enhance the flow of chi.

In the United States acupuncture gained public attention in 1971, when a well-known columnist, James Reston, underwent an emergency appendectomy in Beijing and described acupuncture’s effectiveness in alleviating severe pain. In 1986, the NIH Consensus Development Conference on the Integrated Approach to the Management of Pain identified acupuncture as an effective tool for many types of pain and other symptoms. These days, Americans make up to 12 million visits to acupuncturists per year. Allopathic physicians perform or refer to acupuncture primarily in cases of pain and substance abuse, and most research on acupuncture has focused on these treatments.

Stimulating particular points using needles, pressure, heat, or electric waves causes the measurable release of endorphins into the blood. The activation of small myelinated nerve fibers sends impulses into the spinal cord, midbrain, pituitary, and hypothalamus. Various endorphins block incoming pain information through the release of serotonin, norepinephrine, and possibly GABA. Studies demonstrate that acupuncture is especially, though not exclusively, effective with myofascial pain and trigger points.

During acupuncture, patients should not feel pain from the therapy itself. The frequency of treatment will vary according to the particular condition. Treatments last from 5 to 30 minutes, and from 1 to 20 needles may be used. Although some patients experience immediate pain improvement, others require at least 3 treatments. Risks associated with this treatment include fainting, bruising, pain, infection, or injury to underlying tissue, but these reactions are rare. Acupuncture is contraindicated in the treatment of malignancy, mechanical obstruction, fulminant infection, hemorrhagic diseases, or conditions that require surgical repair.

Hypnosis
Hypnosis, a therapy used in pain management since the mid-1800s, is based on conscious relaxation in association with patient-designed suggestions and exercises. Hypnosis assists patients in obtaining deep levels of relaxation, which...
often leads to more peaceful sleep, increased energy, and a diminished experience of pain.

In the initial consultation, the patient discusses specific problems and begins to develop trust and a rapport with the hypnotherapist. The prerequisites for treatment are the capacity for a degree of concentration, imagination, and a willingness to participate fully. The patient remains in control of the process throughout the session, which reduces any risk for adverse reactions.

The hypnosis session can be directed toward the patient’s emotional and physical stress either separately or simultaneously. Through deep breathing techniques, the patient is guided physically and cognitively into the relaxation of each part of the body. In a deeply relaxed state the subconscious mind is open to receiving the beneficial suggestions constructed by the patient and therapist beforehand. The hypnotherapist suggests changes in the behaviors, thoughts, and feelings of the patient. The patient, in hypnosis, will accept only those suggestions that are relevant to his or her needs. By maintaining awareness throughout the session, the patient is later able to reinforce the hypnotic experience independently.

A conducive setting for hypnosis includes a quiet space, muted lights, a comfortable chair, and uninterrupted time. Although the absence of environmental distractions is preferable, hypnosis can provide positive results in almost any setting. A session usually lasts between 20 and 60 minutes. Patients have reported feelings of heightened emotional well-being, deep relaxation, and reduction of physical pain. A greater number of sessions generally leads to greater improvement.

Research has not yet been able to delineate the mechanism underlying hypnosis’ effect, but it appears to be more effective than placebo. Studies have shown that those with the greatest capacity to relax respond best.

**Conclusion**

Acupuncture and hypnosis can benefit some patients with pain; patients with myofascial pain or headache respond well to acupuncture, and highly anxious patients who want to actively participate in and control their care respond well to hypnosis. The clinician should realize that while not every therapeutic modality will work on everyone, there are options, including pharmacotherapy, physical therapy, and complementary therapies. Given the multitude of complementary therapies available and the incomplete understanding of their mechanisms and efficacy, clinicians unfamiliar with them might want to familiarize themselves with the services available in their communities. If the physician considers acupuncture, hypnotherapy, and other complementary therapies as adjuvants to nonsteroidal anti-inflammatory drugs and opioids for the treatment of pain, he or she may find patients more grateful and the practice of medicine more interesting.

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