# “All of me is wrong”

## The Concept of Total Pain

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*Extension of Community Healthcare Outcomes

I have no actual or potential conflict of interest in relation to this presentation.

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# Objectives

- Define and explore the concept of “total pain”
- Highlight the relevance of “total pain” to palliative care
- Offer practical tips to better manage “total pain”

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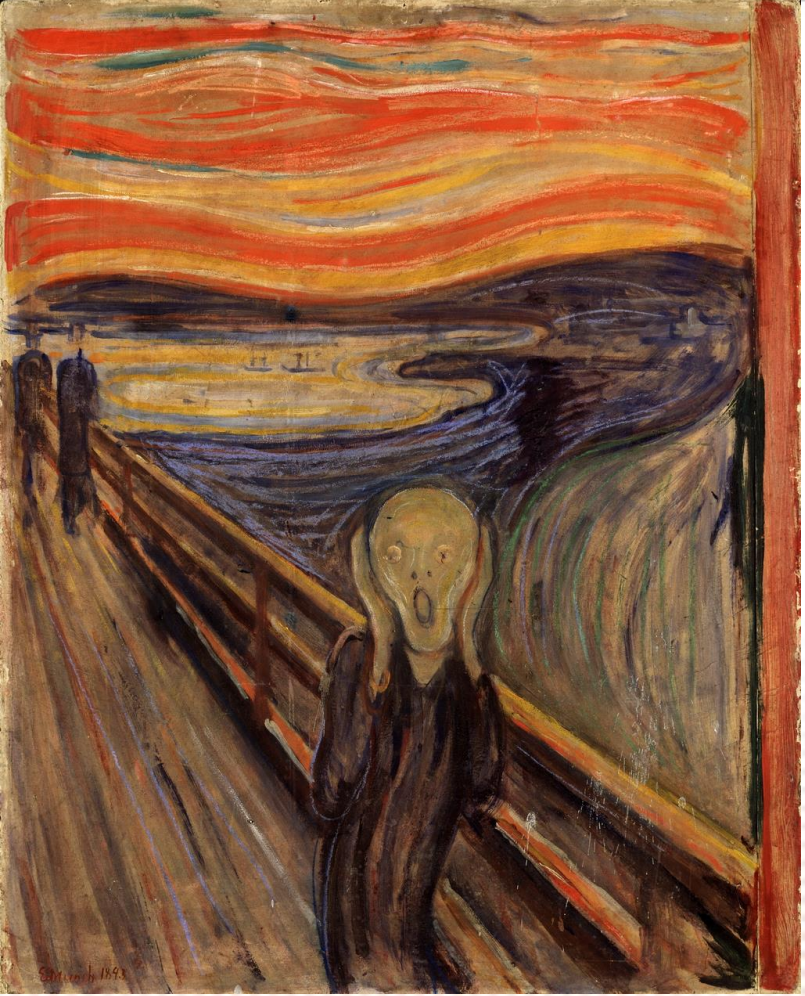

# What is pain?

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“Skrik” by Edvard Munch, 1896; National Gallery, Oslo, Norway

# Pain

Latin “poena” -> punishment

Ancient Greek “poine” -> penalty, fine

# Pain concepts, throughout history

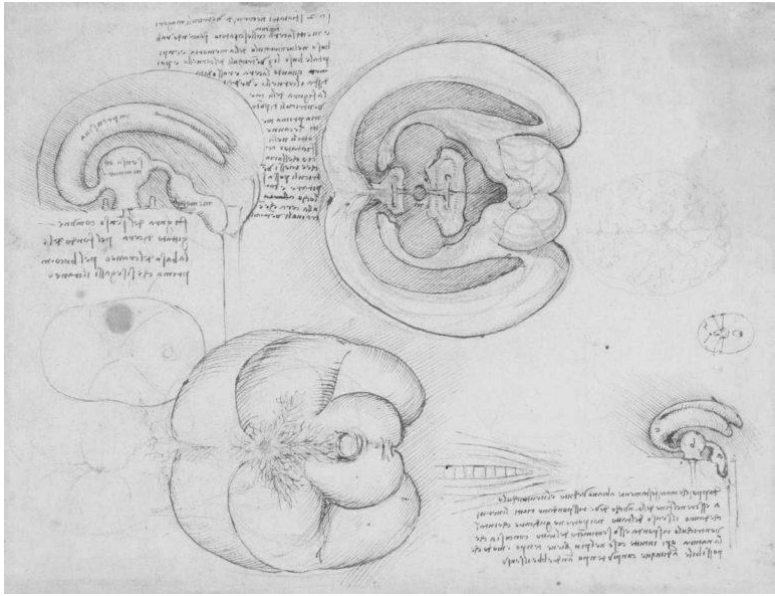
1 - Pre-modern

2 - Modern/biological

3 - Contemporary

From the Elgin Marbles, by Phidias, c 447-438 BCE, British Museum, London

# Modern/Biological



Anatomical Studies, by Leonardo da Vinci, c. 1510, Royal Library, Windsor

Nerve endings send predictable pain signals

Useful warning of tissue damage

Treat the cause and you will relieve the pain

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“Ether Day”, by Robert Hinckley, 1882-1893, Francis A. Countway Library of Medicine, Cambridge, MA

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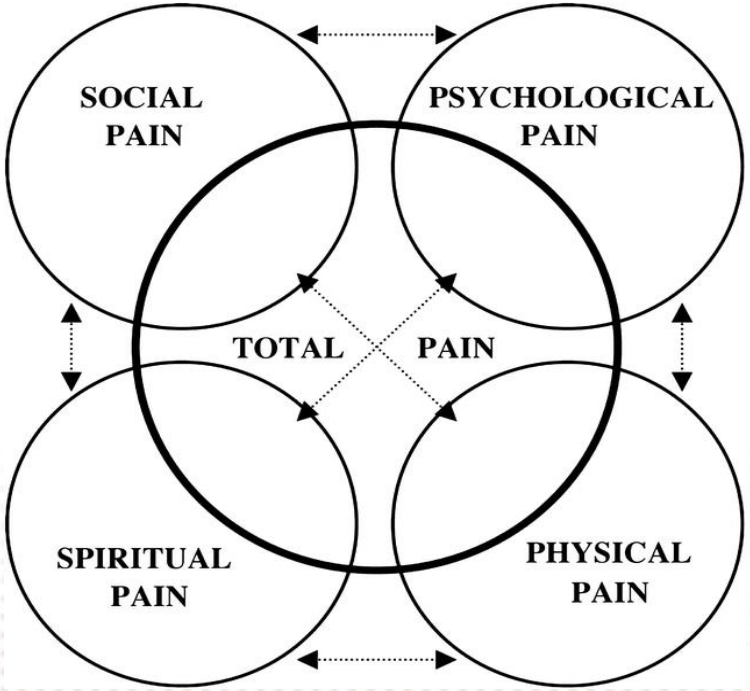
# Total Pain




Mehta & Chan “Understanding the concept of total pain”
*Journal of Hospice and Palliative Nursing, 10 (1) Jan/Feb 2008*

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# Case

43 y/o man w metastatic colorectal cancer

- s/p chemotherapy, tumor debulking, radiation
- Comes to the ED for worsening abdominal pain
- Home medications:
  - Methadone 5mg po BID
  - Dilaudid po 4-6mg po q4h prn
  - Gabapentin 200mg po TID
  - Acetaminophen 650mg po q6h

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# Pain Assessment

OPQRST

OLDCART

CLORIDE

SOCRATES

# Pain Assessment

OPQRST**U**

How is the pain affecting you?

- ADLs, work, play, school, relationships, etc.

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# Sean Mackey, MD - “Stanford Five”

Cause - Patient’s belief about cause of pain (cancer, muscular strain, etc.)

Meaning - Meaning of pain from patient’s perspective (association of pain with ongoing tissue damage, sinister ideas of pathology)

Impact - Impact of pain from patient’s perspective (has it disrupted their social/vocational/recreational activities)

Goals - Patient’s goals (to be happier, to be less depressed, to go back to work or school)

Treatment - Patient’s perception of appropriate treatment (including whether the patient wishes to be referred to other specialists)

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From “The Pain Chronicles” by Melanie Thernstrom, Picador, 2010, p. 243-44

# Case - Analgesics Tried

Methadone slowly titrated to 10/5/10

Dilaudid IV (3mg q2h prn), PCA (up to 0.7mg q30min prn) - stopped b/c of myoclonus, constipation, somnolence

Fentanyl patch (up to 75mcg/hr) - stopped b/c of somnolence, constipation

Oxycodone 20mg q4h scheduled

Gabapentin increased to 600mg TID

Tylenol 650mg q6h

Celebrex 100mg BID

Marinol 5mg BID - stopped b/c of hallucinations

Baclofen 10mg po TID - stopped b/c of somnolence

Effexor 150mg daily

Heat packs

Lidocaine patches

Ketamine infusion (up to 0.3mg/kg/hr)

Intrathecal pump - not place b/c of ?benefit

Bowel regimen:

- Miralax
- Senna
- Bisacodyl supp
- Milk of magnesia
- Enemas
- Methylnaltrexone

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# Is he religious?

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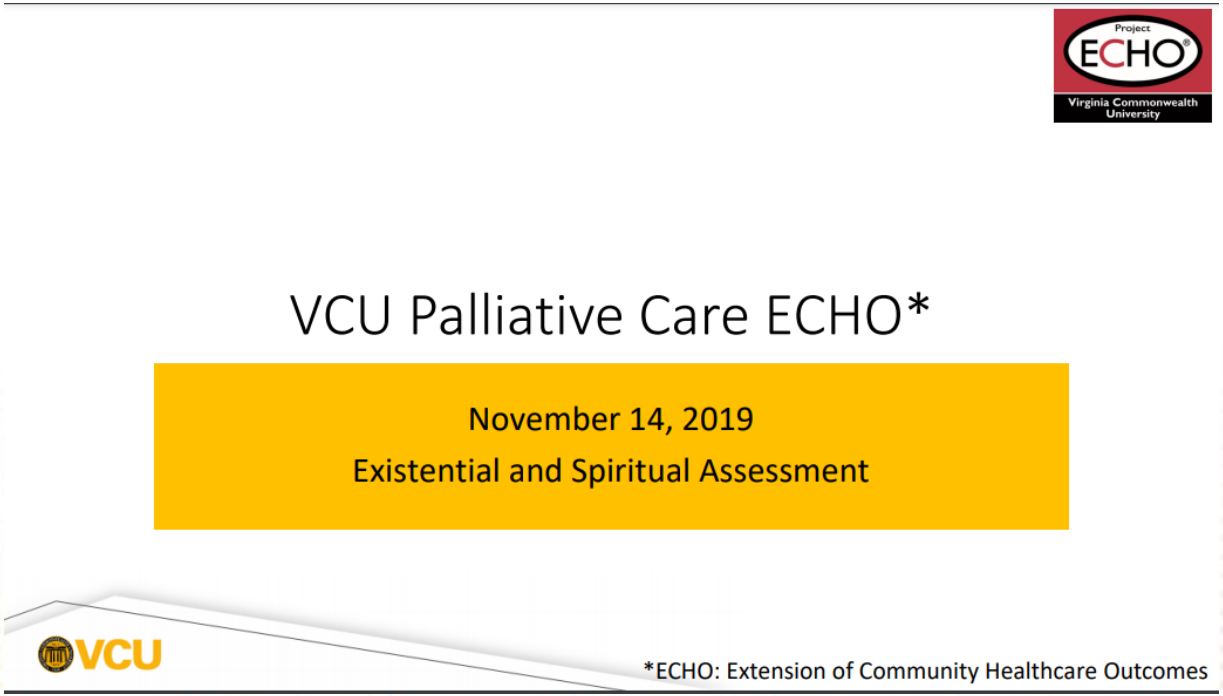
# Spiritual assessment




https://www.vcuhealth.org/-/media/media/file/11_14-palliative-spritual-assessment.ashx

# Defining Spirituality

Daniel Sulmasy, MD, PhD: “experience of something other than themselves, outside them or inside them but not equivalent of them”

- Sulmasy D. *The Healer’s Calling: A Spirituality for Physicians and Other HealthCare Professionals.* New York: Paulist Press; 1997:11

- Connectedness

- Meaning

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# Spiritual/Existential Assessment

How are your spirits?

Are you suffering?

Are you at peace?

Are you frightened by all this?

What are you most frightened of?

What do you worry is going to happen to you?

What is the worst thing about all this?

What keeps you strong?

What gives your life meaning and purpose?

What do you value?

How would you answer the question: Why am I here?

What do you see as your identity? How would you answer the question, Who am I?

What are you most proud of?  What are your regrets?

What do you think this illness is about?

Are there questions or conversations you wish people (e.g. family, friends, clinicians) were asking or talking with you about, but they have not?

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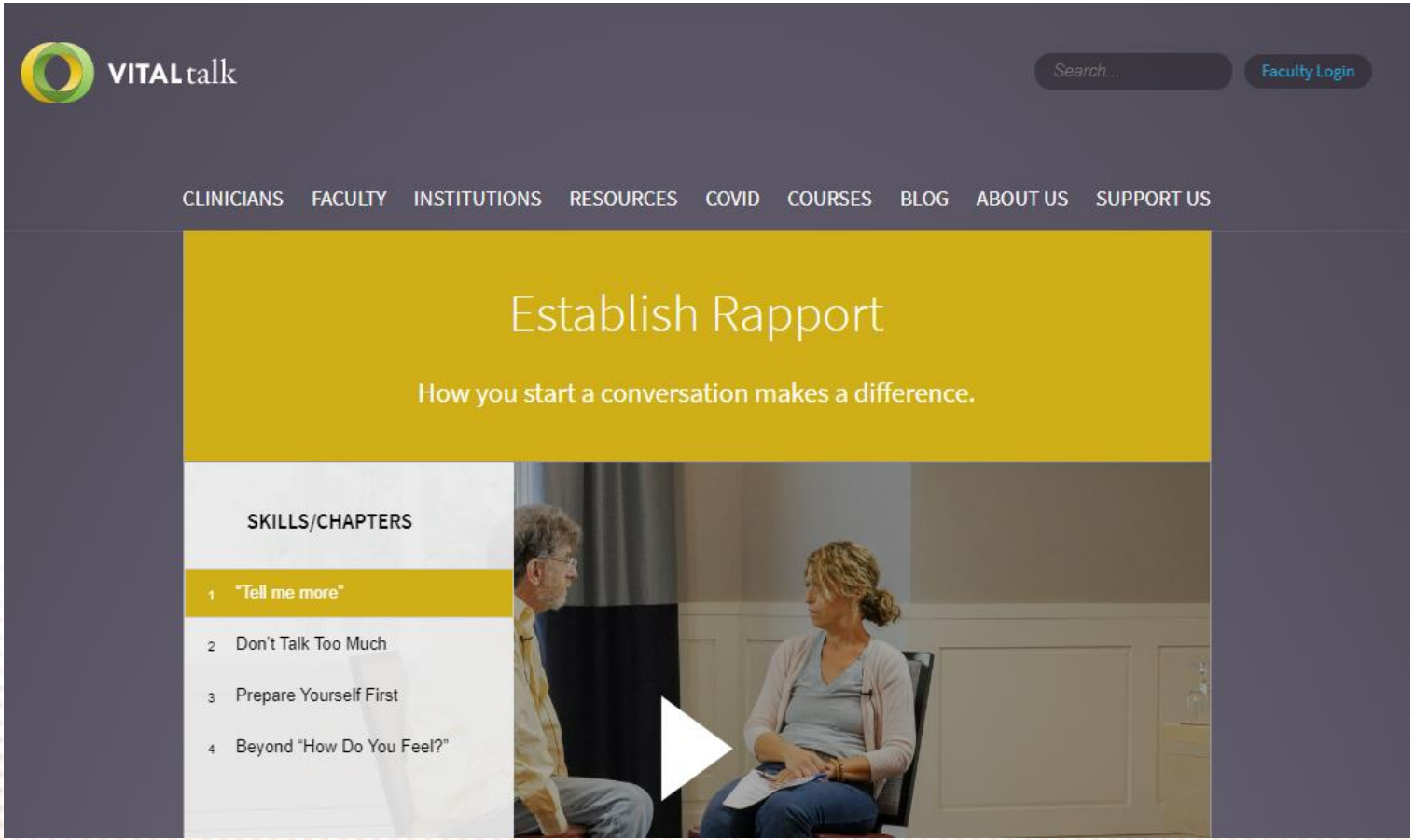


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https://www.vitaltalk.org/topics/establish-rapport/

# Treating Existential/Spiritual Suffering

Compassion and non-judgmental attention

Dignity Therapy

Logotherapy

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# Case

The oncology team had explained his cancer was incurable

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The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

# Patients' Expectations about Effects of Chemotherapy for Advanced Cancer

Jane C. Weeks, M.D., Paul J. Catalano, Sc.D., Angel Cronin, M.S., Matthew D. Finkelman, Ph.D., Jennifer W. Mack, M.D., M.P.H., Nancy L. Keating, M.D., M.P.H., and Deborah Schrag, M.D., M.P.H.

## ABSTRACT

**BACKGROUND**

Chemotherapy for metastatic lung or colorectal cancer can prolong life by weeks or months and may provide palliation, but it is not curative.

**METHODS**

We studied 1193 patients participating in the Cancer Care Outcomes Research and Surveillance (CanCORS) study (a national, prospective, observational cohort study) who were alive 4 months after diagnosis and received chemotherapy for newly diagnosed metastatic (stage IV) lung or colorectal cancer. We sought to characterize the prevalence of the expectation that chemotherapy might be curative and to identify the clinical, sociodemographic, and health-system factors associated with this expectation. Data were obtained from a patient survey by professional interviewers in addition to a comprehensive review of medical records.

**RESULTS**

Overall, 69% of patients with lung cancer and 81% of those with colorectal cancer

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# Collusion in doctor-patient communication about imminent death: an ethnographic study

ABSTRACT ● **Objective** To discover and explore the factors that result in the "false optimism about recovery" observed in patients with small cell lung cancer. ● **Design** A qualitative observational (ethnographic) study in 2 stages over 4 years. ● **Setting** Lung diseases ward and outpatient clinic in a university hospital in the Netherlands. ● **Participants** 35 patients with small cell lung cancer. ● **Results** False optimism about recovery usually developed during the first course of chemotherapy and was most prevalent when the cancer could no longer be seen on x-ray films. This optimism tended to vanish when the tumor recurred, but it could develop again, though to a lesser extent, during further courses of chemotherapy. Patients gradually found out the facts about their poor prognosis, partly by their physical deterioration and partly through contact with fellow patients in a more advanced stage of the illness who were dying. False optimism about recovery was the result of an association between physicians' activism and patients' adherence to the treatment calendar and to the "recovery plot," which allowed them to avoid acknowledging explicitly what they should and could know. The physician did and did not want to pronounce a "death sentence," and the patient did and did not want to hear it. ● **Conclusion** Solutions to the problem of collusion between physician and patient require an active, patient-oriented approach by the physician. Perhaps solutions have to be found outside the physician-patient relationship itself—for example, by involving "treatment brokers."

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# Talking with Patients about Dying

Thomas J. Smith, M.D., and Dan L. Longo, M.D.

Self-deception is a valuable personal coping tool. It allows us to aspire to significance, strive for new knowledge, and yearn to make a lasting contribution to the world despite the certainty of our inevitable end. Indeed, no arduous task would ever be undertaken if we were unable to exaggerate the benefits we expect from it and underestimate the difficulty of its accomplishment. Daniel Kahneman has called this the "planning fallacy," our tendency to overestimate benefits and underestimate costs, and thus make foolish decisions to embark on risky pathways.

People have an optimistic bias. This optimism helps us cope with the inevitability of death, which Ernest Becker has described as our "denial of death." So if you ask a dying person what they believe will be the outcome of a treatment that they have already decided to take, what do you think they will say?

In this issue of the *Journal*, Weeks and colleagues did just that.[1] They asked nearly 1200 patients with metastatic lung cancer or colorectal cancer whether they expected their treatment to cure them. The authors found that the majority of patients with these conditions with a poor prognosis regardless of therapy felt that their treatment course was likely to "cure" them. Perhaps the problem here is the word "cure." To a patient with advanced disease, it may mean something very different from eradication of all disease without return. It may mean an end to pain or a hope for a better tomorrow with fewer incapacities. If patients actually have unrealistic expectations of a cure from a therapy that is administered with palliative intent, we have a serious problem of miscommunication that we need to address.

This brings up other questions. Were the patients who were surveyed not actually told that their disease was incurable? Or were they not told effectively, did they choose not to believe the message, or did they fully understand the message but respond too optimistically to the questions posed by a stranger? It is probably a com-

# Smith and Longo recommend:

Stating prognosis at first visit

Appointing someone in the office to ensure there is a discussion of advance directives

Helping to schedule a hospice-info visit within the first three visits

Offering to discuss prognosis and coping (“what is important to you”) at each transition

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# Pain Psychology

MBSR

CBT

Biofeedback

Acceptance + Commitment Therapy

Mind-Body Therapies (structured exercise, yoga, tai chi, motor control exercise, progressive relaxation, and electromyography biofeedback)

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# “Containment” Technique

70 y/o w ovarian cancer

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# Trauma-informed Care

Recognize

Assume

Act accordingly

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# Behavioral Activation

- Do more, feel better

- E.g. dignity therapy

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Kengsington Hospice, Toronto, ON

Antonella da Messina, 1477-9, Gemaldegalerie, Dresden

Sandro Botticelli, 1474, Staatliche Museen, Berlin

El Greco, 1576-9, Palencia, Spain

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# Suffering and salutogenesis

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## SUMMARY

*In considering pain and suffering, some considerations will appear about epistemological beliefs shaping the clinical practices of health-care workers. With this, we try to understand the usual omission of human suffering in the training of many health professionals. So, we emphasize the role of the pathogenic paradigm in how human suffering is viewed in health care. In contrast to those who see suffering only as pathogenic, we defend that suffering can be a source of significant learning for both the sufferer as well as those who undertake caring in certain circumstances. We therefore argue that it is necessary to educate for health and not only for illness, choosing a holistic paradigm: Aaron Antonovky's salutogenic model that encloses positive aspects of human suffering when it is lived with an internal sense of coherence.*

*Key words*: suffering; pain; salutogenesis; internal sense of coherence

## INTRODUCTION

This paper shows, on the one hand, the limits of biomedicine in understanding and caring for suffering and, on the other, it provides a theoretical frame in which suffering is presented as a (even a micro one) signal of damage. Pain is considered as a manifestation of physiological negative changes which can usually be diagnosed by the use of technology. On this view, pain implies physiological abnormality in the structure of an organ or in tissues. That is why many health pro-

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Special Report

# Taking Psychedelics Seriously

Ira Byock, MD, FAAHPM[1,2]

**Abstract**

***Background:*** Psychiatric research in the 1950s and 1960s showed potential for psychedelic medications to markedly alleviate depression and suffering associated with terminal illness. More recent published studies have demonstrated the safety and efficacy of psilocybin, MDMA, and ketamine when administered in a medically supervised and monitored approach. A single or brief series of sessions often results in substantial and sustained improvement among people with treatment-resistant depression and anxiety, including those with serious medical conditions.

***Need and Clinical Considerations:*** Palliative care clinicians occasionally encounter patients with emotional, existential, or spiritual suffering, which persists despite optimal existing treatments. Such suffering may rob people of a sense that life is worth living. Data from Oregon show that most terminally people who obtain prescriptions to intentionally end their lives are motivated by non-physical suffering. This paper overviews the history of this class of drugs and their therapeutic potential. Clinical cautions, adverse reactions, and important steps related to safe administration of psychedelics are presented, emphasizing careful patient screening, preparation, setting and supervision.

***Conclusion:*** Even with an expanding evidence base confirming safety and benefits, political, regulatory, and industry issues impose challenges to the legitimate use of psychedelics. The federal expanded access program and right-to-try laws in multiple states provide precendents for giving terminally ill patients access to medications that have not yet earned FDA approval. Given the prevalence of persistent suffering and growing acceptance of physician-hastened death as a medical response, it is time to revisit the legitimate therapeutic use of psychedelics.

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# Case

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# Take-Home Points

Pain is perceived not just from physical sensations

“Total pain” = physical, social, psychological, spiritual

Pain should be assessed by exploring the elements of “total pain”

“Total pain” interventions take time

Listen

Help make connections and meaning

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