Re-Defining Pain:
Living Fully in the Context of Palliative Care

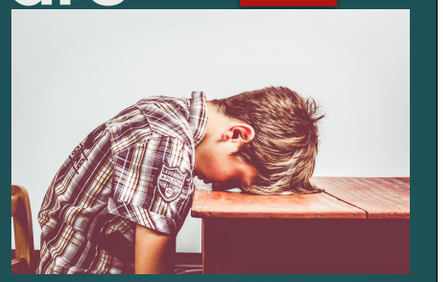
Andrea Diulio, PhD & Timothy Wright, PsyD
Well-Being Through Illness and Dying
October 20th, 2017

Friday Kahlo was diagnosed with polio at six, which resulted in a withering leg that became repeatedly infected and was eventually amputated later in her life. At 18 she had a devastating bus accident, the injuries of which she would never fully recover and would bring her chronic pain for the rest of her life. The accident also prevented her from bearing children and she endured a number of miscarriages. Frida's difficult and extremely passionate relationship with renowned womaniser Diego Rivera, also brought her deep emotional anguish.

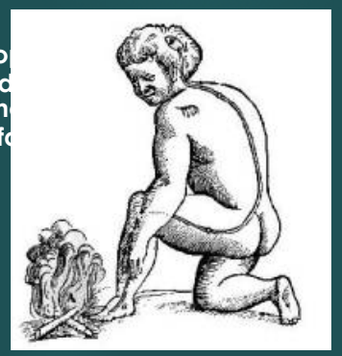
Objectives

- What is Pain (in Palliative Care)?
- Broadening the pain paradigm
- Learning to live more fully: Clinical tools for pain management in palliative care
- Caring for the Person at the end of life

Pain and Palliative Care



- Psychologists not prescribers…
- Pain and Suffering
  - Prescriber and Chaplain?
- Palliative Care vs. End of Life Care?
  - "Palliative care is specialized medical care for peo
    serious illness. This type of care is focused on provid
    from the symptoms and stress of a serious illness. Th
    improve quality of life for both the patient and the fa
    definition.
- Comm MIS onception of Pain



Center to Advance Palliative Care (CAPC) https://www.capc.org/payers-policymakers/what-is-palliative-care/
•Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

WHO definition of palliative care
•Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

•Palliative care is required for a wide range of diseases. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

•Pain is one of the most frequent and serious symptoms experienced by patients in need of palliative care. Opioid analgesics are essential for treating the pain associated with many advanced progressive conditions. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate to severe pain at the end of their lives

•https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3505611/

Pain and Palliative Care

- What type of pain are we talking about?
  - Acute AND Chronic Pain
  - Pain AND Suffering
- Moving beyond narrow definition of p
  - Total Pain (Rome, 2011)
- Bio-Psycho-Social Model of Pain
  - "Pain is a distressing experience a with actual or potential tissue dam sensory, emotional, cognitive, and components"

Acute Pain	Chronic Pain
Less than 3 months	More than 3 months
Is a symptom	Is a condition
Identified cause; body's response to injury	May develop after incident; may have known or unknown cause
Diminishes with healing and responds to treatment	Persists beyond expected healing time and/or despite treatment

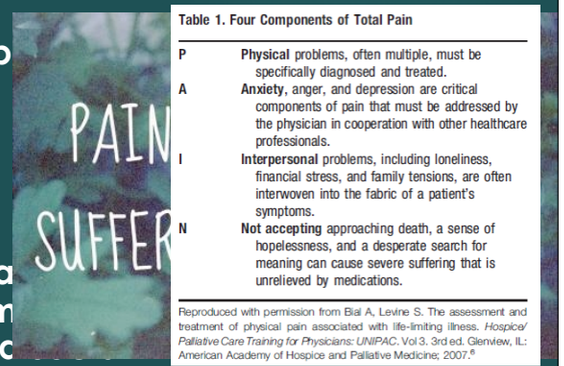


Table 1. Four Components of Total Pain

P	**Physical** problems, often multiple, must be specifically diagnosed and treated.
A	**Anxiety**, anger, and depression are critical components of pain that must be addressed by the physician in cooperation with other healthcare professionals.
I	**Interpersonal** problems, including loneliness, financial stress, and family tensions, are often interwoven into the fabric of a patient's symptoms.
N	**Not accepting** approaching death, a sense of hopelessness, and a desperate search for meaning can cause severe suffering that is unrelieved by medications.

Reproduced with permission from Bial A, Levine S. The assessment and treatment of physical pain associated with life-limiting illness. *Hospice/ Palliative Care Training for Physicians: UNIPAC*. Vol 3. 3rd ed. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2007.[6]

•Common understanding of pain is based upon a model proposed by the philosopher Rene Descartes in the 16th century. This model is fittingly called the *Cartesian model of pain*. Descartes wrote *"The flame particle jumps from the fire, touches the toe, moves up the spinal cord until a little bell goes off in the brain and says, 'ouch. It hurt'."*

•*Pain is bad…* Utility of pain - Congenital insensitivity to pain – lower life expectancy. Hereditary sensory and autonomic neuropathy – frequent ulcers untreated

The International Association for the Study of Pain's widely used definition states: "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."[1] "Pain is a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components"

Explaining Pain

Moseley, 2007

1. Pain does not provide a measure of tissue health
2. The experience of pain is moderated by biopsychosocial factors
3. The relationship between pain & tissue damage is weakened as time passes
4. Pain is correlated with the perception of bodily damage

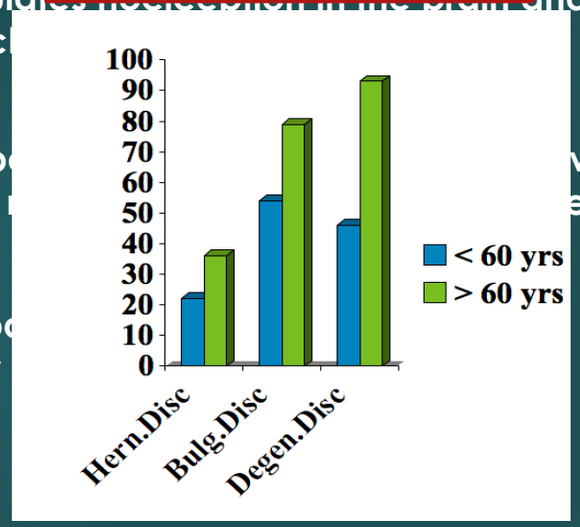
Modern Pain scientist

4 qualities of pain important to remember when talking about, conceptualizing, and treating pain

Not a measure of tissue health

Abnormal MRI in Asymptomatic Adults –

- Injury stimulat… …nd often initiates a c…
- However, p… …vity do not have a … …ealth
- Reported p… nociceptor …

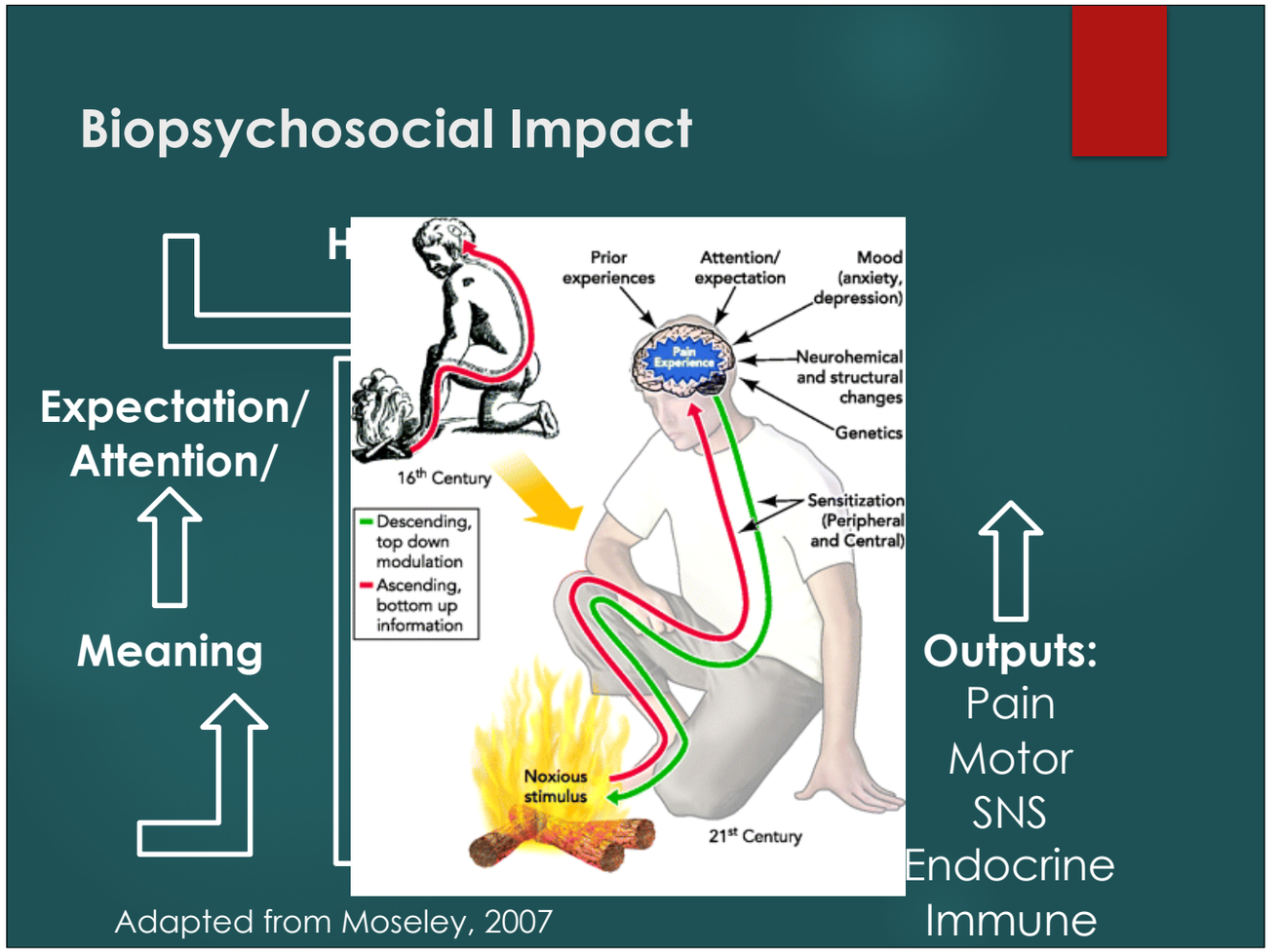


Boden SD et al., J Bone Joint Surg Am 1990;72

specific receptors send threat signals to the spinal cord and the brain. (No –see-ception)

- In graduate school professor studies acquired capability to tolerate pain and correlation to SI, found that tolerance for extreme temps differed by location NE (cold) vs SE heat

- Imaging isnt everything
    - Sowing seeds of doubt derby 0 complain – car accidents whip lash
    - Damage occurs slowly overtime brain does not send out these danger signals



- hazing, initiation, exercise, sports, sadomasochistic sexual practices, sports & war-related stories, child birth

Attention, anxiety, expectation – placebo of taking a analgesic in future, -- bring more or less into focus

****** Meaning of pain – believing pain to be an accurate indicator of tissue damage is associated with higher pain ratings
- Cognitive interpretation, indicator of tissue damage, catastrophic

Answers the ? of how dangerous

evidence of danger to body tissue can increase pain and any credible evidence of safety to body tissue can decrease pain

noxious laser stimuli to their foot, the prior (and deceitful) advice that a particular stimulus site was ‘thin-skinned and vulnerable’ resulted in a higher likelihood of pain (allodynia) and more intense pain to a fixed stimulus (hyperalgesia) than advice to the contrary, even though skin thickness did not really vary at all

In remission – pain in belly – is this pancreatic cancer returning

Less Reliable with Time

- Nervous system is dynamic
- Pain receptors are sensitized as pain persists
  - Hyperalgesia
  - Allodynia

-Nerve cells become more sensitive as pain persists & can fire with no external input

-Proprioceptive representation of the pained body part in sensory cortex changes

-Hyperalgesia: sensitization to painful stimuli
-Allodynia: nonpainful stimuli perceived as painful

-Chornic pain is a maladaptive memory

-Pain can be over protective

-Relate to ptsd

Perception of Injury

- When threat of bodily harm is present a range of responses occur
  - Pain is one output of the CNS
- Pain depends on the perceived degree of threat
- Pain is a motivator of behavior aimed at protecting the body

Pain is real, but is an inkling, rather than evidence of damage

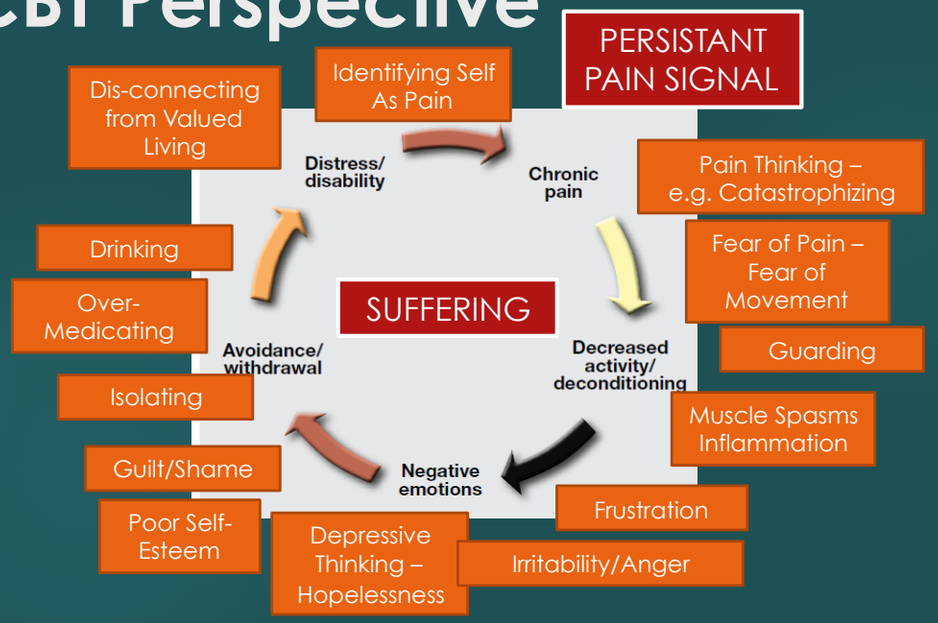
co-existence of several potential protective systems, of which pain is one, but the only one that the sufferer necessarily knows has been engaged

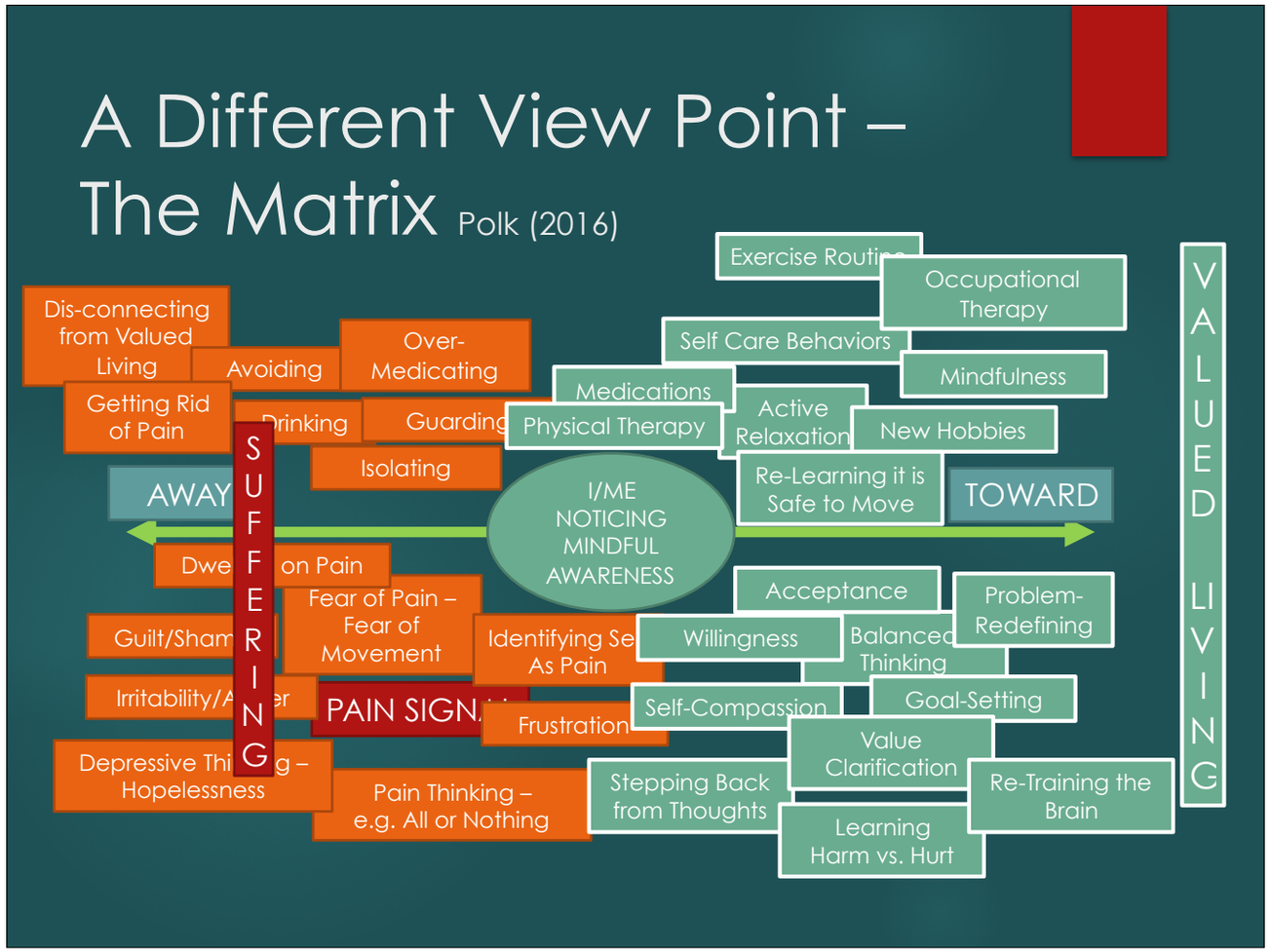
-Inflammatory mediators, change in blood flow, immune mediators

-When functioning correctly serves a protective role

-marker of the perceived need to protect body tissue

Chronic Pain Cycle
A CBT Perspective

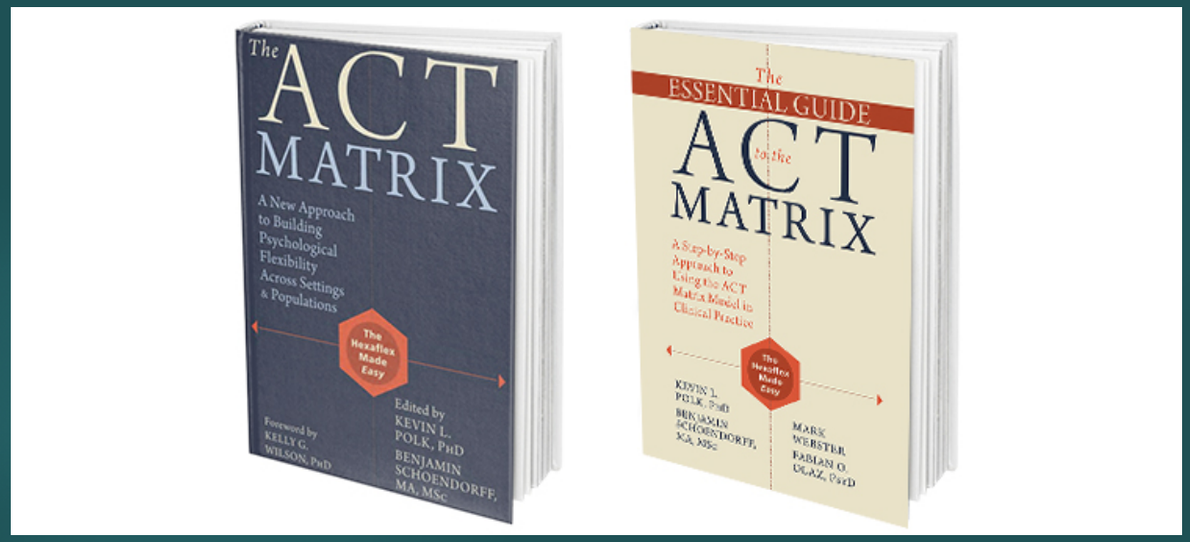


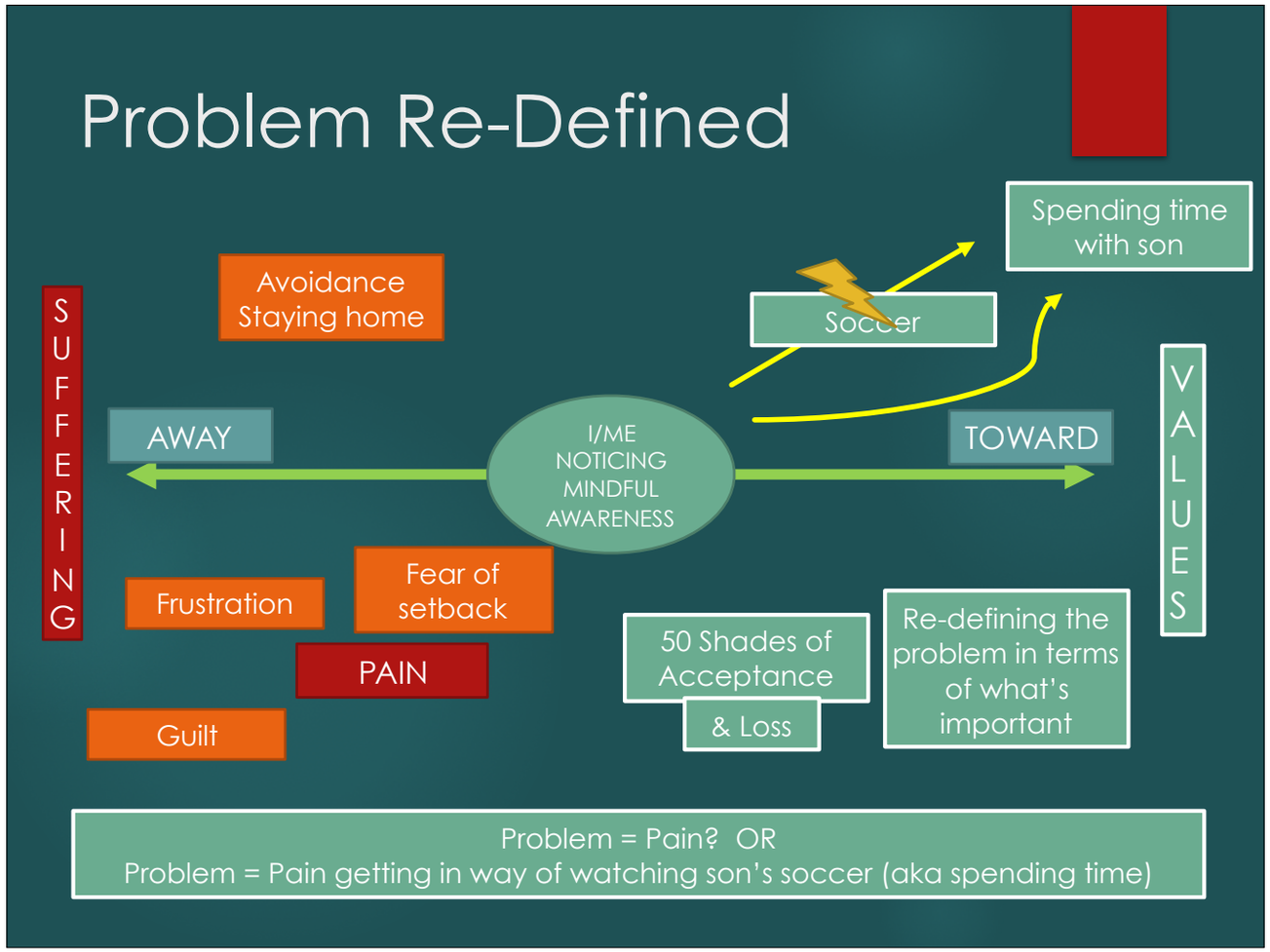


Acceptance and Commitment Therapy (Hayes, Strohsal, Wilson, 2012)

Matrix Points:

- One value you want to move Toward
- One unwanted experience you try to get Away from
- Who's doing the Noticing and Awareness
- Struggle with Pain – short term fix – long term disconnect
- Fear of pain – fear of movement – stop moving
- Help re-learn how to start moving again, re-connect with what's important (VITALITY)
- Combo move
- List techniques:
    - Defusion, acceptance, behavioral engagement, clarify values, active relaxation
    - Present moment awareness – mindful awareness – center of circle of health
    - Changing our relationship to Pain


The
ACT
MATRIX
A New Approach to Building Psychological Flexibility Across Settings & Populations
The Hexaflex Made Easy
Edited by KEVIN L. POLK, PhD BENJAMIN SCHOENDORFF, MA, MSc
Foreword by KELLY G. WILSON, PhD
The
ESSENTIAL GUIDE
to the
ACT
MATRIX
A Step-by-Step Approach to Using the ACT Matrix Model in Clinical Practice
The Hexaflex Made Easy
KEVIN L. POLK, PhD
BENJAMIN SCHOENDORFF, MA, MSc
MARK WEBSTER
FABIAN O. OLAZ, PsyD



Redefining the problem or barrier – in relation to the value
For example:
MS sx - pain, weakness, fatigue - show up when attempting to play soccer
problem as MS sx or as MS sx that get in the way of spending time with my son

Physical metaphor of walking into the barrier – stuck focused on the barrier.
"Tell me to what you pay attention and I will tell you who you are" Jose Ortega y Gasset or
"What you think, you become" Buddha

Targets = letting go of specific behavior, mindful self-compassion, apply time-based pacing, PT/stretches, or developing alternative SMART goal

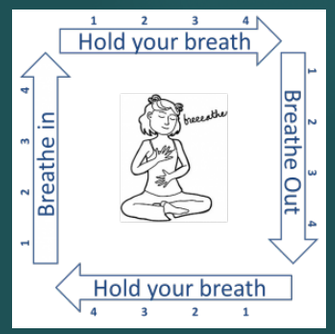
Valued Behavior Interventions

- Branstetter-Rost (2009) – Increased pain tolerance within values framework **
  - Broadening attentional focus, to include value, promotes flexibility
- Practice Skills (Hayes, et al., 2012):
  - Value Clarification – dart board, life compass, eulogy exercise, written value statements
  - Valued Action Goal Setting
    - SMART: Specific and supportive, measurable and meaningful, achievable, resources, time-defined
  - Compassionate self-awareness – moving gently

Deactivate Stress Response

- Overactive SNS can result in greater muscle tone, attention to area of concern, and pain sensitization

- Relaxation tools can deactivate the SNS
  - Diaphragmatic Breath
  - Four Square Breathing
  - Progressive Muscle Relaxation



*Helpful to practice skills when relaxed in order to build confidence before applying during pain event

Muscle tension, inflammation can increase swelling and lead to increase in activity of pain carrying receptors

“Pain is an unpleasant conscious experience that emerges from the brain when the sum of all the available information suggests that you need to protect a particular part of your body”

Air enters the lungs and the chest rises and the belly expands during this type of breathing. Diaphragmatic breathing is also known scientifically as *eupnea, which is a natural and relaxed form of breathing in all mammals. Eupnea occurs in mammals whenever they are in a state of relaxation, i.e. when there is no clear and present danger in their environment.*

It is a way of interrupting the 'Fight or Flight' response and triggering the body's normal relaxation response."

End of Life

- Explore what is most important to Patient
- Education on use of opioid and sedative medication
  - When opioids are used appropriately the risk of respiratory depression is unlikely
  - Dose is titrated for relief of a specific symptom
    Sykes & Thorns, 2003
- Distraction
  - Visual and tactile mindfulness exercises

N Sykes, A Thorns - The lancet oncology, 2003 – Elsevier The use of opioids and sedatives at the end of life (review)

patients who have symptoms that prove intractable, either because treatment is ineffective or the treatment itself is intolerable.

Inappropriately dubbed slow euthanasia or terminal sedation; both suggest that patients' lives are shortened by treatment - 4

Fohr concluded that when opioids are used appropriately for pain relief, the risk of respiratory depression is more myth than fact.2

Bercovitch and colleagues found no difference in survival between patients receiving high doses and those receiving low doses.8

Morita and colleagues found no significant difference in the survival of patients receiving different doses of opioids.10

doctrine of double effect is used as an ethical justification
for the specific risk of foreseeable life shortening as a result of
a medical treatment. However, we suggest that there is no
evidence that the use of opioids or sedatives in palliative care
requires the doctrine of double effect as a defence.

Pain at the end of life is inescapably interwoven with, and often amplified by, multiple levels of emotional and spiritual angst as the inevitability of death looms

Conclusion

- Pain is not an indication of injury
- The way we think/talk about pain can change the experience
- Tx focus on living
  - Compassionate self-awareness
  - Learning to hold pain experience lightly and gently – a hypothesis, not conclusion
  - Re-learning to move – toward what and who matters
  - Active Relaxation
  - Encourage autonomy and dignity at EOL
  - Normalize and provide education on medication at EOL

References

Branstetter-Rost, A., Cushing, C., Douleh, T. (2009). Personal values and pain tolerance: Does a values intervention add to acceptance? Journal of Pain, 10, 887-892.

Meyer R, Ringkamp M, Campbell JN, Raja SN. Peripheral mechanisms of cutaneous nociception. In: McMahon SB, Koltzenburg M. (eds) Textbook of Pain, 5th edn. London: Elsevier, 2006; 3–35

Moseley, G. L. (2007). Reconceptualising pain according to modern pain science. Physical Therapy Reviews, 12(3), 169-178

Moseley, G. L., & Butler, D. S. (2015). 15 years of explaining pain – The past, present and future. The Journal of Pain, 16, 807–813.

Polk, K., Scheondorff, B., Webster, M., & Olaz, F. (2016). Essential Guide to the ACT Matrix. New Harbinger, NY.

Rome, R., Luminais, H., Bourgeois, D., & Blais, C. (2011). The role of palliative care at end of life. The Oschner Journal, 11, 348-352

Sykes N, Thorns A. The use of opioids and sedatives at the end of life. Lancet Oncol 2003;4:312–318.

Wilkie, D., & Ezenwa, M. (2012). Pain and symptom management in palliative care and at end of life. Nurs Outlook, 60, 357-364.

Questions

Andrea Diulio, PhD
Transitions Professional Center
adiulio@transitionspc.com

Timothy Wright, PsyD
Transitions Professional Center
VA Portland Health Care System
Timothy.Wright6@va.gov