
The background of the slide is a gradient of warm colors, transitioning from a light orange at the top to a deep red at the bottom. Scattered throughout this background are various silhouettes of autumn leaves in shades of brown, tan, and light orange, some appearing as if they are falling or floating.

"Softening" Suffering: Treating Physical, Psychological, Existential And Spiritual Suffering in the Palliative Care Patient


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The background of the slide features a vertical color gradient transitioning from a light orange at the top to a deep red at the bottom. Scattered across this gradient are various silhouettes of leaves and foliage in a muted, brownish-orange tone. Some leaves are large and detailed, while others are smaller and more abstract, creating a natural, autumnal feel.

"I have no financial or other conflicts of interest related to this presentation. Any mention of off-label use of drugs will be clearly mentioned as such."

Our Objectives...

- 1. Define four key types of suffering in the Palliative Care patient
- 2. Describe one intervention that can be helpful in softening psychological suffering.
- 3. Describe two interventions that can be helpful in “softening” existential or spiritual suffering.



"The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet."

Rachel Naomi Remen, Kitchen Table Wisdom

The Paradox of suffering....

- “Life threatening illness is an assault on the whole person—physical, psychological, social and spiritual. It frequently presents caregiver and sufferer with a paradox: suffering does not correlate with physical well being.”

(Mount et al, Jrnl of Pain & Symptom Management, 2007)

Four types of suffering:

- Physical

- Psychological

- ▣ Existential

- ▣ Spiritual

Physical Suffering (pain)

- Symptoms:
 - Pain
 - Thirst
 - Nausea
 - Constipation
 - Dizziness
 - Dyspnea
- Treatment options
 - Medications
 - Alternative or complementary interventions
 - Other: palliative measures, procedures, etc.

Most likely to be recognized and treated

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What it can look like:

(We all know this—right?)

Psychological Suffering

- Symptoms

- Fear of (physical) pain
- Fear of death
- Worry about family
- Loss of independence
- Diminished self esteem
- Loss of usefulness
- Anxiety

- Treatment options

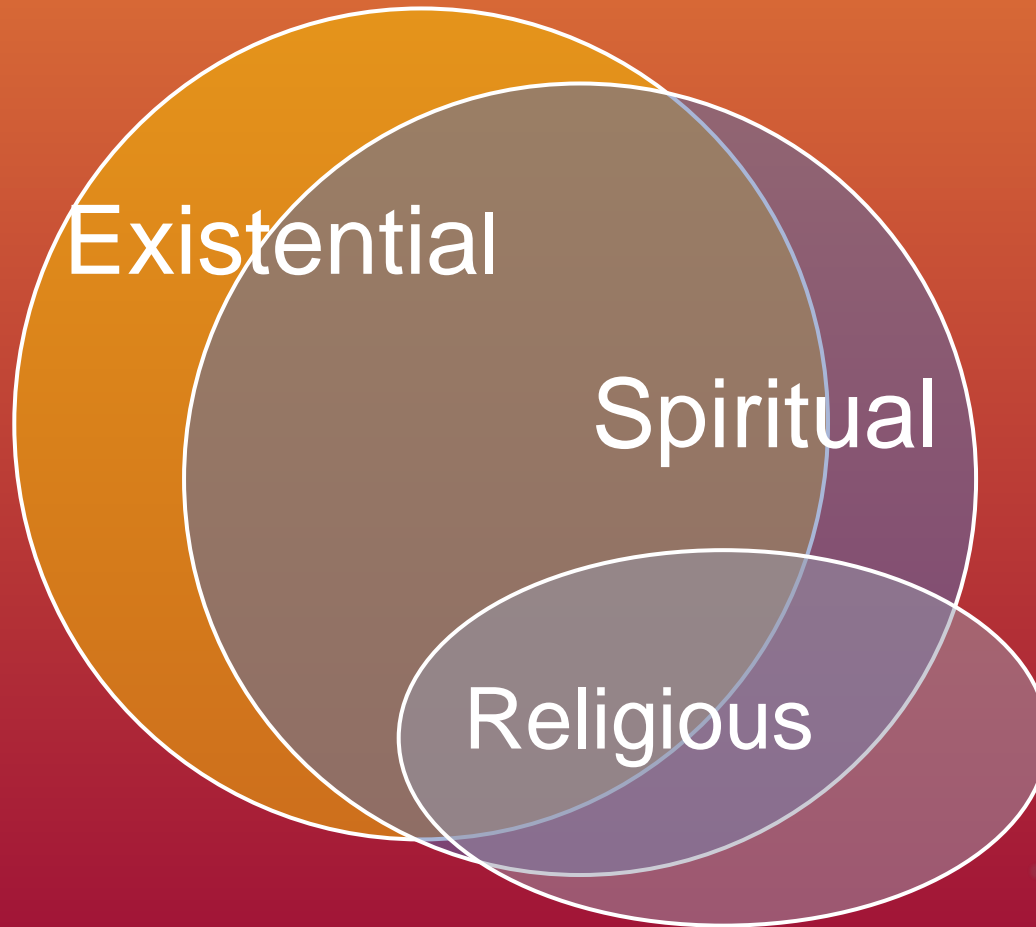
- Open conversation with health care providers and family members
- Psychological support and reassurance

Less likely to be recognized and treated

What it can sound like:

- I don't want to be a burden...
- Do I have enough life insurance?
- I can do it myself, thank you OR
Let me do it myself--dammit!
- Leave me ALONE!
- Is this going to hurt? Can you give me something?
- I'm not good for anything anymore...

Existential, Spiritual & Religious



Existential Suffering

- Symptoms

- Loss of self identity
- Loss of purpose
- Loss of personhood
- Loss of hope
- Loss of dignity
- Fear of disfigurement

- Treatment Options

- Open conversation with health care providers
- Open communication with family members
- Chaplain consult

Much less likely to be recognized and treated

How we can recognize:

Major issues of existential suffering:

- Death anxiety
- Loss/change
- Loss of control
- Dignity of the self
- Fundamental aloneness
- Altered relationships
- Search for meaning
- Mystery about what seems unknowable

Kissane, "The Relief of Existential Suffering, JAMA 10/2012

What it can look like:

- Passivity
- Giving up – there is a difference between “giving up” and “being finished”
- Anger (in men) or despair (in women)
- Grief & sadness (a normal and appropriate response)
- Depression (a clinical condition requiring treatment)

Patient story

Mr X (Stage 4 Esophageal cancer, New Dx)

Spiritual (Religious) Suffering

- Symptoms

- Questioning beliefs
- Fear of afterlife.
Uncertainty regarding life after death
- Anger with God

- Treatment Options

- Ask patient about spiritual beliefs, talk openly about spiritual matters
- Chaplain consult (please?)

Least likely to be recognized and treated

What it can sound like:

- ◉ What do you think happens when you die?
- ◉ You know, I've done a lot of terrible things in my life...
- ◉ I've prayed and prayed and no one's answering
- ◉ Do EVERYTHING – I don't want to die!
- ◉ Why did God do this (let this happen) to me?
- ◉ Cynicism or bitterness

George, WW II veteran - "*Can God forgive me?*"

Patient Story

“Losing God” – Schwartz Center Rounds

- ▣ One patient’s story of a spiritual crisis...
 - “health care providers do not have to be religious in order to help patients deal with a spiritual crisis.”
 - “to ignore spirituality in dealing with dying patients denies the mystery of life and presents an adequate response to suffering.”
 - “The “dark night of the soul” is common theme...
 - It’s OK to get angry at God (or just angry in general!) but we often suppress anger in dying patients...

One more type of suffering: Suffering imposed by Health Care

- Article from Intl Jrnl of Nrsng: A study of Breast Cancer Patients' Experiences:
 - In addition to other four types of suffering, a 5th emerged:
suffering assoc w/ health care experiences
 - Quality physical care w/o emotional care
 - *"This empirical study found that in many cases health care causes increased suffering....the women's experiences of suffering tended to be of similar seriousness as their experiences of suffering in relation to having cancer."*
 - "perceived as almost violation by the patients"

- ...*"it is extremely important that you're not just patient number 32 that day."*
- ...*"If you are not seen as anything but a physical thing, not seen in your suffering, that really makes the suffering more intense, for there you are. I thought sometimes I could just cut a piece of myself off and send that, I don't have to go along myself, for they are not interested in me, are they."*

Viktor Frankl – Man's Search for Meaning

Frankl's Story (p. 9 -11)

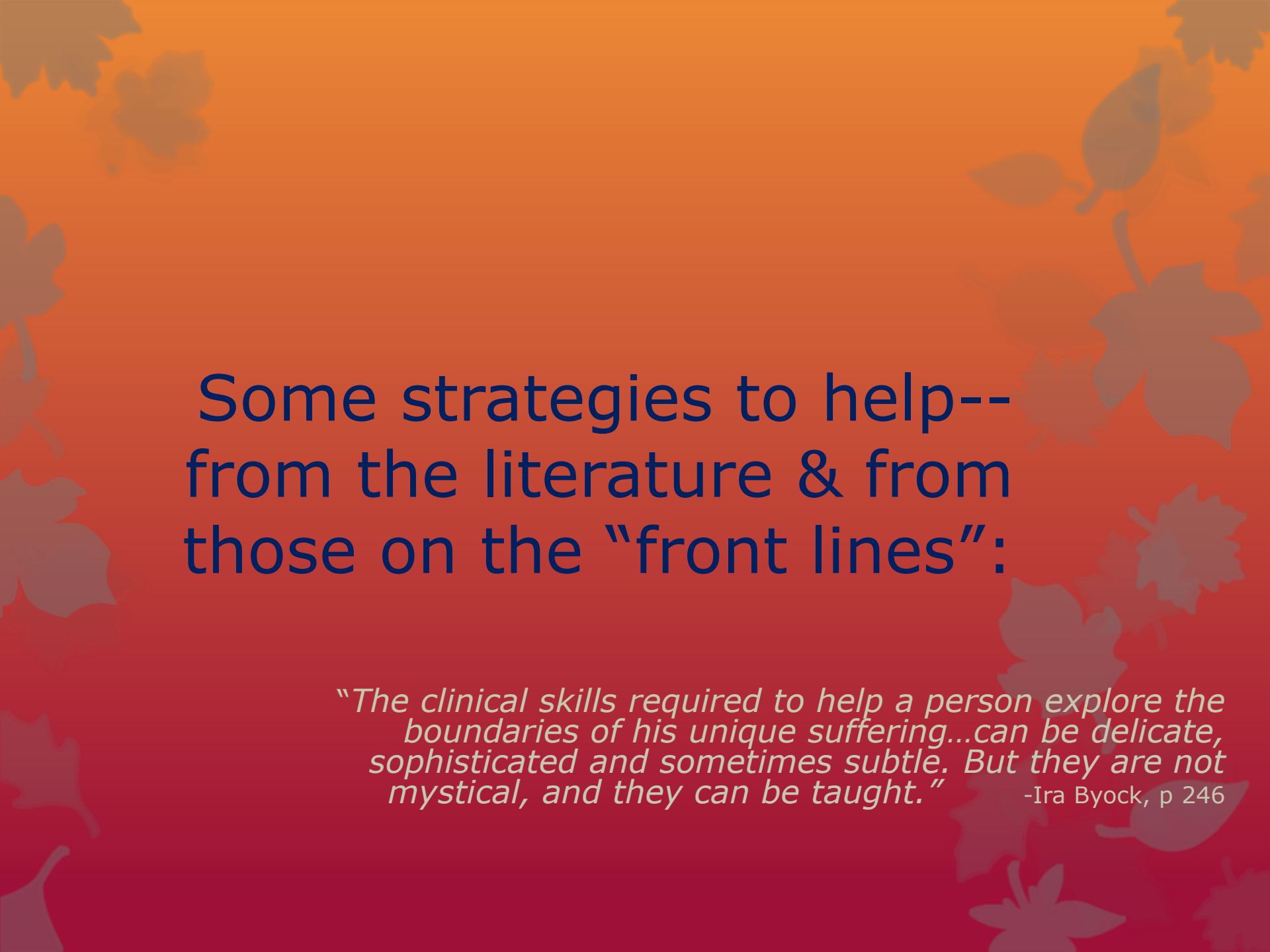
Frankl's wisdom:

- *Loss of hope can be deadly: p 96*
- *Meaning and Purpose can be life sustaining. p 100*
- *"When we are no longer able to change a situation...we are challenged to change ourselves."
(pp 86 & 87)*

A word about Physician Assisted Suicide...

- "Society has become fixated on assisted suicide as the solution to suffering at life's end."
- The request should be the beginning of the conversation... a plea for help
- It's the WRONG QUESTION
- At what point does the "option" create the "obligation?"

● Byock p. 245 - 246



Some strategies to help--
from the literature & from
those on the “front lines”:

“The clinical skills required to help a person explore the boundaries of his unique suffering...can be delicate, sophisticated and sometimes subtle. But they are not mystical, and they can be taught.”

-Ira Byock, p 246

1. Encourage patients to:

- Help others. Helping others allows one to feel useful and shifts focus off self.
- See suffering as a life challenge
- Nurture personal relationships.

"The lived experiences of spiritual suffering and the healing process among Taiwanese patients with terminal cancer" Chio et al,
Journal of Clinical Nursing, 2007.

2. Borrow a page from Religious belief

(Secular) Western Culture:
Suffering = Bad

However...



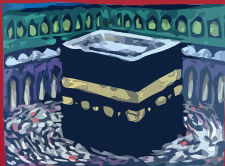
Eastern thought (particularly Buddhism) life = suffering--integral part of existence, can lead to transcendence.



Christianity: suffering can be redemptive & sacred, release from suffering occurs not in this world, but in the next.



Judaism: suffering is something which must be accepted, for the sake of others, and for the sake for the community, as part of God's plan.



Islam: suffering is an intrinsic part of life. Two views: either the painful result of sin, or it is a test. Either way, it has meaning.

--Byock "Dying Well"

3. “Soften Suffering:”

- Acknowledge & validate suffering: don’t cheer someone up, don’t trivialize or minimize, avoid the “*tyranny of the positive*.” Meet people where they are.
- Enter into the experience – be truly present. Stop trying to “*fix it*.”
- Listen well.
- Compassion – latin root: *com passio*.
- Offer realistic HOPE “my hope for you is...”

Larraine Wright, “Softening Suffering,” from Keynote address: 8th International Family Nursing Conference

4. Make a Connection

- Minimize uncertainty
- “Legacy”
- Support expression of fear *“what is the toughest/worst/hardest/scariest part of this for you?”*
- Affirm Strength: *“Tell me about a time in your life when you overcame something really tough...?”*
- Support patient in seeking meaning (but do not impose meaning!)
- Make something happen

Balfour, et al, “Healing Connectings, On Moving from Suffering to a Sense of Wellbeing” - In Jrnl of Pain & Symptom Management, April 2007.

The Four things Every Dying Person
needs to hear...

Thank you

I love you.

I forgive you.

Please forgive me.

- Ira Byock, MD "The Four Things that Matter Most"

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“It all Begins with Hope”

Ronna Fay Jevne, Ph.D, p.172

Bibliography

Books

Byock, I., Dying Well – Peace and Possibilities at the End of Life, Riverhead Books, NY, 1997.

Frankl, V., Man's Search for Meaning, Pocket Books, NY, 1984.

Jevne, R., It all Begins with Hope, Lura Media, SD, CA, 1991

Articles

Arman, M., et al, "Suffering related to health care: a study of breast cancer patients' experiences." Int J Nurs Pract. 2004 Dec;10(6): 248-56

Chio, C., et al, "The Lived experiences of spiritual suffering and the healing process among Taiwanese patients with terminal cancer," J. Clin Nurs. 2008 Mar; 17(6):735-43

Chochinov, H., Dying, dignity and new horizons in palliative and end of life care," CA Cancer J Clin, 2006 Mar-Apr;56(2): 84-103

Mount, B., et al. "healing Connections: on moving from suffering to a sense fo well-being." J. Pain Symptom manage. 2007 Apr; 33(4):372-88

Penson, R., et al, "Losing God," Oncologist, 2001;6(3):286-97.

Strang P. , et al, "Existential Pain—an entity, a provocation, or a challenge?", J Pain Symptom Manage, 2004 Mar;27(3):241-50

Wright, L.M., "Softening Suffering through Spiritual Care Practices: one Possibility for healing families," Jrnl of Fam Nurs., 2008 14(4):394-411.