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

Beverly M. Beltramo, D.Min BCC
Director, Spiritual Support Services
Oakwood Health System
"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, JrnI of Pain & Symptom Management, 2007)
Four types of suffering:
- Physical
- Psychological
- Existential
- Spiritual

Kon, et al, 2010
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
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
- 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?”
“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.

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

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”
“It all Begins with Hope”

Ronna Fay Jevne, Ph.D, p.172


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


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


