Psychosocial Distress and Suffering: Hanging on.....Letting go

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Disclosure

Neither I nor any member of my immediate family have significant financial interests in or affiliation with any commercial supporter of this program or with the companies who manufacture competing products or offer competing services.
Learning Objectives

1. To have an increased awareness of the nature of suffering at end of life through an integrative lens of art and science

2. To identify emerging psychosocial-existential paradigms that have contributed to our understanding of suffering

3. To describe a psychotherapeutic process for supporting patients and families at end of life
Questions for Reflection

- What do we mean by suffering?
- How do we know if a person is suffering?
- How does suffering affect those who provide care?
- How can we alleviate suffering at end of life?
Reflection Exercise

Think of an experience of suffering at end of life that you have encountered.

- What was this experience like for the patient and/or family members?
- What was this experience like for you personally?
- Reflect on what this experience has taught you about suffering at end of life.
- What do you think would be helpful for patients, family members, or yourself to deal with suffering at end of life?
What do we mean by suffering?

“It’s torn away a part of my soul....”

(patient with advanced cancer)
To which of these two statements are you drawn?

A. Suffering is a symptom that can be controlled and managed.

B. Suffering is an inherent part of the human condition.
It is easier to say, “My tooth is aching” than to say “My heart is broken.”

C. S. Lewis (1940). The Problem of Pain, p. 144.
To live is to suffer....

To survive is to find meaning in the suffering...

(Viktor Frankl, Man’s Search For Meaning, 1959, 1963)
“All of me is wrong”

Total Pain: suffering related to, and the result of, the person's physical, psychological, social, spiritual and practical state

(Saunders, 1964)
The Nature of Suffering and the Goals of Medicine

- Experienced by persons
- Threat to self
- Affects multiple dimensions

(Cassell, NEJM, 1982)
The Nature of Existential Challenges in Palliative Care: Expressions of Distress

- Worthless
- Shame/body image
- Aloneness
- Alienation

- Loss of control
- Indecisiveness
- Nonadherence
- Dependency fears

- Fear, dread
- Grief, anger
- Panic
- Avoidance

- Loss purpose
- Loss of role
- Spiritual doubt
- Desire to die

Kissane et al. Handbook of Psychiatry in Palliative Medicine 2009, p. 325
The Nature of Existential Challenges in Palliative Care: Adaptive

- Dignity
- Acceptance
- Growth
- Support

- Responsibility
- Committed
- Accept Tx
- Ask for help

- Courage
- Resilience

- Fulfillment
- Accomplish
- Transcend
- Commit to life

The Self
Free choice
Anxiety
Meaning

Kissane et al. Handbook of Psychiatry in Palliative Medicine 2009, p. 325
The Nature of Existential Challenges in Palliative Care: Maladaptive

- Low self-esteem
- Personality Disorder
- Family/Rel dysfxn

- Subst. abuse
- OCD
- Phobias
- Anxiety

The Self

Free choice

Anxiety

Meaning

- Anxiety
- Depression
- Adjustment disorders

- Adjust D/O
- Demoraliz.
- Depression
- Suicidality

Kissane et al. Handbook of Psychiatry in Palliative Medicine 2009, p. 325
5 D’s of Suffering

- depression
- despair
- distress
- desire for hastened death
- demoralization
Distress

Normal Distress
vulnerability
sadness
fears

Severe Distress
depression
anxiety
panic
social isolation
existential crisis

(Holland et al., 2003; NCCN, 2008)
## Erikson's Stages of Psychosocial Development

<table>
<thead>
<tr>
<th>Approximate Age</th>
<th>Psycho Social Crisis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant - 18 months</td>
<td>Trust vs. Mistrust</td>
</tr>
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<td>18 months - 3 years</td>
<td>Autonomy vs. Shame &amp; Doubt</td>
</tr>
<tr>
<td>3 - 5 years</td>
<td>Initiative vs. Guilt</td>
</tr>
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<td>5 - 13 years</td>
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<td>21 - 39 years</td>
<td>Intimacy vs. Isolation</td>
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<tr>
<td>40 - 65 years</td>
<td>Generativity vs. Stagnation</td>
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<td>65 and older</td>
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Compassion & Wisdom vs. Disgust & Disdain
Demoralization Syndrome (Kissane, 2004)

- Meaninglessness
- Hopelessness
- Desire for hastened death
How do we know if a person is suffering?

Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful...

(Frank, 2001, p. 355)
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chochinov et al</td>
<td>1995</td>
<td>Will to live</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Desire for hastened death</td>
</tr>
<tr>
<td>Bayes et al</td>
<td>1997</td>
<td>How long did yesterday (this morning, afternoon, evening, night) seem to you?</td>
</tr>
<tr>
<td>Steinhauser et al.</td>
<td>2006</td>
<td>Are you at peace?</td>
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</tbody>
</table>
# Multidimensional Assessments

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<thead>
<tr>
<th>Indicator</th>
<th>Measure</th>
<th>First Author</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress</td>
<td>Distress Thermometer + Checklist</td>
<td>NCCN (2008)</td>
</tr>
<tr>
<td>Depression</td>
<td>Beck Depression Inventory</td>
<td>Beck (1988)</td>
</tr>
<tr>
<td>Demoralization</td>
<td>Demoralization Scale</td>
<td>Kissane (2004)</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>Beck Hopelessness Scale</td>
<td>Beck (1974)</td>
</tr>
<tr>
<td>Desire for Hastened Death</td>
<td>Schedule of Attitudes Towards Hastened Death</td>
<td>Rosenfeld (1999)</td>
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</tbody>
</table>
Edmonton Classification System for Cancer Pain

- Mechanism of pain
- Incident pain
- Psychological distress
- Addictive behavior
- Cognitive function

(Fainsinger et al, 2010; Nekolaichuk et al, 2005)
Fig 2. Relationship of psychological distress with related concepts.
Psychological Distress
Guidelines

- Relationship with pain
- Multidimensional

Fig 2. Relationship of psychological distress with related concepts

Psychological Distress Guidelines

- Relationship with pain
- Multidimensional
- Relationship with suffering
- Relationship with coping
- Physical symptom expression


Fig 2. Relationship of psychological distress with related concepts
The Edmonton Symptom Assessment System – What Do Patients Think?

- Pain
- Tiredness
- Nausea
- Depression
- Anxiety
- Drowsiness
- Appetite
- Wellbeing
- Shortness of breath

(Watanabe, Nekolaichuk & Beaumont, 2009)
How does suffering affect those who provide care?
Why is it that some suffering strikes us blind and leaves us mutilated, while other suffering enriches our life?

(Soelle, 1975, p. 2)
Total pain
Refractory suffering

Health Care Provider

Patient
Vicarious Trauma

PTSD

Health Care Provider

Total pain
Refractory suffering

Patient

accumulative transformation

(McCann & Pearlman, 1990; Pearlman & Saakvitne, 1995; Swetenham et al, 2011)
Vicarious Trauma
PTSD

Health Care Provider

impaired
communication

accumulative
transformation

Patient

Iatrogenic suffering
Total pain
Refractory suffering
Vicarious Trauma
PTSD

Health Care Provider

impaired
communication
accumulative
transformation

Patient

Iatrogenic suffering
Total pain
Refractory suffering

Team dynamics
Boundary issues
Vicarious Trauma
PTSD

Health Care Provider

Iatrogenic suffering
Total pain
Refractory suffering

Patient

Impaired communication
Accumulative transformation
Grief
Burnout
Compassion fatigue
Moral distress

Team dynamics
Boundary issues
Change
↓
Loss
↓
Grief

- anger
- rage
- sadness
- fatigue
- fear
- isolation
No Time to Grieve

Change

↓

Loss

↓

Grief

- anger
- rage
- sadness
- fatigue
- fear
- isolation

Where is your grief?
How can we alleviate suffering at end of life?

I want to be there for my daughter, yet I don’t want to keep living like this. I wish it were over. I feel so guilty.

(palliative patient)
Story is the only thing we have at the end of our lives, and it is everything.

Jevne & Nekolaichuk, 2001
What do you hear in the stories you listen to?

- Grief
- Anger
- Distress
- Moral distress
- Anxiety
- Ambivalence
- Confusion
- Bullying
- Depression
- Suicidal ideation
- Burnout
- Vicarious trauma
- Fatigue
- Frustration
- Isolation
What do you hear in the stories you listen to?

- Healing
- Wholeness
- Love
- Forgiveness
- Nature
- Being guilt free
- Freedom from fear
- Thankfulness

- Hope
- Integrity
- Peace
- Grace
- Dignity
- Wisdom
- Compassion
- Acceptance/Surrender
How can we alleviate suffering?

- Dignity
- Spirituality
- Will to live
- Hope
- Meaning
Psychotherapeutic Approaches at End of Life

- Existential individual and group therapy (Frankl, 1963)
- Dignity therapy (Chochinov, 2012)
- Supportive group therapy in advanced metastatic cancer patients (Spiegel & Goodwin et al., 2000; 2001)
Grief & Loss

Life Review & Reminiscence

Legacy Work

Hope-enhancing strategies

Hopeful environments

Tappings

God is tapping my shoulder
Non-Specific Therapeutic Factors

Therapist

“Helping the Whole Person”

Patient

“Achieving a Sense of Healing”

Dichotomies at End of Life

Connected

Meaningful

Certain

Uncertain

Isolated

Meaningless

(Nekolaichuk et al 1999; 2004, in press)
Dichotomies at End of Life

- **Connected**
  - Meaningful
  - Certain
- **Uncertain**
- **Isolated**
- **Holding On**
  - "wanting to live"
- **Letting Go**
  - "wanting to die"

(Nekolaichuk et al 1999; 2004, in press)
Hope
(Nekolaichuk, 2010)
How might things change over time?

What might be a hopeful sign?

What might be possible...yet?

(Nekolaichuk, 2010)
Dichotomies at End-of-Life

Holding On “wanting to live”

Meaningful

Certain

Waiting

Watching

Hope

Uncertain

Letting Go “wanting to die”

Isolated

Meaningless

(Nekolaichuk, 2010)
Lesson 1

Each time you meet someone, it is a totally new experience.
Lesson 2
Show up. Leave your baggage at the door....and don’t forget to breathe.
Lesson 3

It is okay to feel comfortable with being uncomfortable.
Lesson 4
Silence can be your greatest ally.
Lesson 5

Recognize your triggers – and your touchstones.
Lesson 6
Look for “signs” of hope.
Lesson 7
Look after yourself.
You are your greatest gift.
Lesson 8
Hold on to something that keeps you grounded....
....as you let go of the need to know.
Reflection Exercise
Think of an experience of suffering at end of life that you have encountered.

- What was this experience like for the patient and/or family members?
- What was this experience like for you personally?
- Reflect on what this experience has taught you about suffering at end of life.
- What do you think would be helpful for patients, family members, or yourself to deal with suffering at end of life?
Summary

- Psychological distress is one component of a larger overarching experience of suffering.
- Many of our current tools are not comprehensive enough to screen for suffering.
- Our ongoing exposure, as health care professionals, to others’ suffering, may impact our own health.
- A significant component of our relationships with patients and families is based on non-specific therapeutic factors.
Future Directions

- What are some of the factors associated with suffering at end of life (e.g. psychological distress & pain)?
- How do we screen and assess for suffering in our patients and families?
- What outcomes should we be measuring?
- How do we strengthen our own hope to help cope with our experiences of suffering at end of life?
Nothing in landscape or life is permanent. We have to expect and anticipate change; there is no cause for despair. Indeed stormy landscapes have a beauty of their own. One just has to look for it. “If you shed tears when you miss the sun, you also miss the stars” said the poet Tagore.

(G. B. Mukherji, Landscape and Life, 2002)