The changing landscape of how we face mortality

The Nature of Suffering

- Threat to life or injury to self, with resultant distress, grief at loss, sense of helplessness and likelihood that the situation will endure
- **Total Pain**: combination of symptoms, impairment & debility resulting in psychological, spiritual and social disruption to equilibrium (Cicely Saunders)
What are some features of Existential Distress?

A Typology of Existential Distress

1. Death anxiety
2. Loss and change
3. Freedom & Autonomy
4. Dignity of self
5. Aloneness & Isolation
6. Altered quality of relationships
7. Search for meaning
8. Mystery about what seems unknowable

• Existential Distress: Threats to self-identity, hopelessness, burden to others, loss of sense of dignity and loss of will to live
• Existential Loneliness: intolerable emptiness, sadness and longing that results from the awareness of one’s fundamental separateness as a human being
Death Anxiety
Fear, apprehension & dread when thinking of dying

Maladaptive Responses
- Anxiety disorders
- Depression
- Protest at uncertainty
- Avoidance of medical care
- Panic w/ physical change

Adaptive Adjustments
- Courageous acceptance
- Mindfulness of the present moment
- Relaxation techniques
- Open awareness of dying

Fear, apprehension & dread when thinking of dying

Freedom & Autonomy
Fear of loss of control, dependency, being a burden

Maladaptive Responses
- Preoccupied by need for control
- Obsessive traits
- Dependency fears
- Distortions of reality
- Indecisiveness

Adaptive Adjustments
- Accepts helpful treatments
- Greater connectedness & intimacy
- Responsibility & Commitment
- Asks for help
- Connectedness

Fear of losing worthiness and respect

Dignity & Integrity of Self
Fear of losing worthiness and respect

Maladaptive Responses
- Distress at disfigurement
- Shame & embarrassment
- Alienation & aloneness
- Perception of being stigmatized

Adaptive Adjustments
- Continuity of self
- Personal growth & resilience
- Acceptance of frailty
- Personal integrity
- Connectedness

Meaning of Life

Pointlessness & loss of purpose

Maladaptive Responses
• Hopelessness
• Demoralization
• Deep anguish & despair
• Desire for hastened death
• Clinical depression

Adaptive Adjustments
• Transcendence
• Gratitude
• Creativity
• Appreciation of beauty
• Legacy
• Purpose-driven goals
• reframing the value of one’s life

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Breitbart W, Applebaum A. Meaning-centered group psychotherapy. Handbook of Psychotherapy in Cancer Care. 2011:137-


A clinical portrait of Demoralization

Characteristics of Demoralization
• An expression of existential distress, characterized by:
  – Hopelessness w/ loss of meaning & purpose
  – Attitude of helplessness, failure, lack of worthwhile future
  – Social isolation
  – Feeling of failure to meet expectations set by the pt or others
  – Reduced adaptive coping abilities
• Persistence for 2+ weeks
• MDD has not superseded as primary disorder

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Clinical Factors in Demoralization

Predisposing Factors

- Poor self-esteem
  - including narcissistic traits
- Avoidant coping style
- Cumulative losses
- Reduced social supports
- Poor symptom management
- Significant toxicity side-effects
- Worsening debility

Perpetuating Factors

- Poor physical symptom control
- Social withdrawal
- Untreated co-morbid depression
- Avoidant coping
- Limited social supports

Why is it important to recognize demoralization?

- Countertransference:
  - Projective identification
  - Patient desire to hasten death corresponds with physician hopelessness and pessimism about the patient
- Decisional capacity may be compromised
- Viable treatment options are available

Demoralization vs. Depression

Demoralization, Anhedonia & Grief are all associated with Depression

- Depression
  - Anhedonia is the traditional hallmark of “biogenic” depression
- Demoralization
  - Subjective incompetence
  - Affective state & maladaptive responses
  - Not a formal disorder or syndrome (yet)
  - Psychosocial factors more predictive (than physical illness itself)
Prevalence of Demoralization vs. Depression

- Outpatients with medical disease (n=807)
  - 30% demoralization, 16.7% major depression
  - 43% w/ major depression had no demoralization
  - 69% w/ demoralization had no major depression

- Demoralization also occurs independent of depression:
  - Demoralization Scale: 7-14% of patient were highly demoralized but not depressed
  - Community Sample (n=419): 21% had high demoralization without elevated Beck Depression Inventory scores


Approaches & Treatments for Demoralization

- Bolster supports: family, community volunteers, home health aids, hospice
- Active symptom management, including comorbid depression
- Restoration of hope:
  - Validating accomplishments, Crafting a coherent life story & Affirming sources of fulfillment
- Therapy
  - Dignity Therapy
  - Meaning-Centered Psychotherapy
  - Interpersonal Psychotherapy
  - Cognitive Behavioral Therapy
  - Mindfulness & Acceptance Therapy


Dignity Therapy

- 3 sessions, 60 min each
- Based on Dignity Protocol
- Audiotaped & transcribed
- Generativity document

Dignity Therapy Protocol

- Themes in the Dignity Protocol:
  - Milestones in your life history
  - Most important roles in your life
  - Anything that still needs to be expressed
  - Hopes for your loved ones
  - Legacy to others


Benefits of Dignity Therapy

- Patients report that Dignity Therapy was significantly more likely to:
  - Better quality of life
  - Enhance sense of dignity
  - Benefit to patients’ families
  - Improve spiritual well-being
  - Lessen sadness or depression

- Dignity therapy not proven to mitigate outright distress


Finding Meaning in Suffering
Meaning-Centered Group Psychotherapy

- Based on Viktor Frankl’s logotherapy
- Treatment for psychological, spiritual & existential distress
- 8 sessions
- Meaning-centered themes
- Active engagement from members

Topics in Meaning-Centered Group Psychotherapy

<table>
<thead>
<tr>
<th>Topic</th>
<th>MCGP</th>
<th>SCP</th>
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<tbody>
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<td>Group Member's Stabilization</td>
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<td>2. Father and Sonship</td>
<td>Group Member's Stabilization</td>
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<tr>
<td>3. Spiritual Sources of Meaning</td>
<td>Coping with Medical Stress and Coping with Pain and Anxiety</td>
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<td>4. Physical Sources of Meaning</td>
<td>Coping with Mortality Anxiety</td>
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<td>5. Anxious Source of Meaning</td>
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<td>6. Guilty Source of Meaning</td>
<td>Coping with Guilt and Resentment</td>
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<tr>
<td>7. Loss, Death, Mortality, and Meaning</td>
<td>Coping with Loss and Mortality</td>
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<tr>
<td>8. Terminal Gronottes, and Hope for the Future</td>
<td>Coping with the Future</td>
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Benefits of Meaning-Centered Group Psychotherapy

- N=253 assigned to MCGP or Supportive Group Psychotherapy
- Significantly greater improvement in:
  - Spiritual well being
  - Quality of life
- Significantly greater reductions in:
  - Depression
  - Hopelessness
  - Desire for hastened death
  - Physical symptom distress
Other forms of Meaning-Centered Psychotherapy

- Individual Meaning-Centered Psychotherapy (ICMP)
  - ICMP had significantly improved spiritual well-being and QOL
- Meaning-Centered Group Psychotherapy for Cancer Survivors (MCGP-CS)
  - Improved personal meaning, goal-orientedness, purpose in life, “fighting spirit” & environmental mastery
  - Reduced helplessness/hopelessness (3mo)
  - Reduced depression (6mo)
- Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C)
  - Addresses existential distress in caregivers
  - Internet delivery model
  - Further studies planned to identify groups in greatest need (e.g. SCT, brain tumors)


Questions & Discussion

Thank You!

Practical Aspects of Palliative Care
September 15, 2017
Keri O. Brenner, MD MPH
MGH Palliative Care & Psychiatry