DEMORALIZATION and EXISTENTIAL DISTRESS IN ONCOLOGY

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non-caring attitudes to life

Disorders of meaning:
- existential despair
- spiritual torpor
- mopeishness
- pointlessness
- acedia
- demoralization

Disorders of affect:
- unhappiness
- depression
- hopelessness
- helplessness
- anxiety
- fear

Is there psychopathology attached to loss of meaning?
How do we conceptualize existential distress?

Presentation plan

1. Typology of existential distress
2. The nature of demoralization
3. Literature review
4. Recent empirical data & validity
5. Treatment approaches
6. Contagion: Demoralized clinicians, teams, families

The nature of existential challenges in palliative care

<table>
<thead>
<tr>
<th>Existential domains</th>
<th>Expressions of distress</th>
<th>Method of adaptation</th>
<th>Potential Psychiatric disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The self</td>
<td>↓worth, shame, aloneness</td>
<td>Dignity, acceptance, supported</td>
<td>Low self-esteem, Depression, Personality Disorder</td>
</tr>
<tr>
<td>2. Free choice</td>
<td>↓control, non-adherent to Px, dependent</td>
<td>Responsibility, adhere &amp; ask for help</td>
<td>Substance abuse, OCD, Phobias, Anxiety</td>
</tr>
<tr>
<td>3. Meaning</td>
<td>Loss of role &amp; purpose, spiritual doubt</td>
<td>Fulfillment, Transcendence</td>
<td>Demoralization, Depression, Suicide</td>
</tr>
<tr>
<td>4. Anxiety</td>
<td>Fear, dread, Grief, anger</td>
<td>Courage, Resilience</td>
<td>Anxiety, Depression</td>
</tr>
</tbody>
</table>

What are these major existential challenges?

- DEATH
- LOSS
- FREEDOM
- DIGNITY
- ALONENESS
- RELATIONSHIPS
- MEANINGLESSNESS
- MYSTERY

Forms of existential distress

1. Death
2. Loss
3. Freedom
4. Dignity
5. Aloneness
6. Relationships
7. Meaninglessness
8. Mystery

- Death anxiety
- Complicated grief
- Loss of control
- Worthlessness
- Profound loneliness
- Conflict & alienation
- Demoralization
- Spiritual doubt & despair
### Features of successful adaptation

1. **Death**
   - Courage
2. **Loss**
   - Adaptive Mourning
3. **Freedom**
   - Accept frailty, loss of independence
4. **Dignity**
   - Sense of worth despite disfigurement
5. **Aloneness**
   - Connection
6. **Relationships**
   - Accompanied by partner, family, friends, community
7. **Meaninglessness**
   - Sense of fulfillment, purpose & creativity in life
8. **Mystery**
   - Reverence for sacred

### Common symptoms

1. **Death anxiety**
   - Fear of process/state of being dead, uncertainty
2. **Complicated grief**
   - Waves of tears, emotionality
3. **Loss of control**
   - Obsessive mastery, fear of dependence
4. **Worthlessness**
   - Shame, body image concerns, burden
5. **Aloneness**
   - Social withdrawal
6. **Alienation**
   - Family conflict/dysfunction
7. **Demoralization**
   - Pointlessness, hopelessness, futility, desire to die
8. **Spiritual doubt & despair**
   - Guilt, loss of faith, loss of connection with the transcendent

### Related psychiatric disorders

1. **Death anxiety**
   - Anxiety, Panic disorders
2. **Complicated grief**
   - Prolonged Grief Disorder; Depression, PTSD
3. **Loss of control**
   - Phobic, Obsessive-OCD, Substance abuse
4. **Worthlessness**
   - Dysthymia, Depression
5. **Loneliness**
   - Dysfunctional family, relationship problems
6. **Alienation**
   - Demoralization syndrome, Depression
7. **Demoralization**
   - Adjustment disorders
8. **Spiritual doubt & despair**

### Range of therapies

- Supportive-expressive – grief, rally support
- Existential psychotherapy – meaning & authentic living
- Psychodynamic therapy – past patterns/schema
- Cognitive-behavioral – maladaptive attitudes
- Interpersonal psychotherapy – role, transition, relationships, grief
- Group therapy – relationships & support
- Couple therapy – marital interactions
- Family therapy – Family Focused Grief Therapy

### Dimensional NATURE of DEMORALIZATION

**Change in morale** spans a **spectrum** of mental states:

- **Disheartenment** [mild loss of confidence]
- **Despondency** [starting to lose hope]
- **Despair** [lost hope]
- **Demoralization** [lost purpose & given up]

### Case study of demoralization

- Elderly veteran with multiple SCC’s head & neck
- Loss of nose & both ears
- Enlarged neck nodes with facial palsy
- Embarrassed, yet avoided prosthesis
- Housebound, isolated, bored
- Life’s pointless now, desire to die
Demoralization - a morbid state

The severe end of the ‘morale’ spectrum of mental states is pathological in its nature -
- it is maladaptive
- a source of considerable personal distress & disability
- leads to greater harm through deterioration and suicide

Pathway to demoralization

**EXTERNAL**
- Stressful event/situation
- Cannot change situation
- ? seek help or stuck
- Appears a failure
- Loss of purpose

**INTERNAL**
- Feeling of threat
- Helpless
- Incompetence
- Shame, isolation
- Meaninglessness, despair

Demoralization literature 1

- Augustine (5thC): to counter Donatists, suicide is evil
- Acedia, accedia, accidie, accedie: tedious meaninglessness
- Role of depression
- Robert Burton: *Anatomy of Melancholia* (1621)

Demoralization literature 2

- Engel 1967: ‘giving up - given up’ complex
- Gruenberg 1967: ‘social breakdown syndrome’ with institutionalisation of the chronically mentally ill
- Schmaler 1972: psychosomatic paradigm of ‘giving up’ → physical illness
- Seligman 1975: ‘learned helplessness’

Demoralization literature 3

- Victor Frankl (1959, 1963) “Suffering itself does not destroy man, rather suffering without meaning”
- Logotherapy – transcend via meaning
- Nietzsche (1974): “He who has a why to live for can bear almost any how”

Demoralization SYNDROME

Kissane et al, 2001

**A.** Affective symptoms of existential distress - loss of meaning or purpose in life, loss of hope.

**B.** Cognitive attitudes of pessimism, helplessness, sense of being trapped, personal failure, or lacking a worthwhile future.

**C.** Conative absence of motivation to cope differently.

**D.** Associated features of social alienation, isolation, or lack of support.

**E.** Persistent Phenomena > 1 - 2 weeks
Demoralization literature 4

- Jerome Frank 1968, 1974: hope & the restoration of morale in psychotherapy
- Dohrenweld et al. 1980: nonspecific distress found in general pop - features = demoralization
- de Figueiredo 1982: subjective sense of incompetence as the hallmark

Developments in coping theory

- Lazarus & Folkman 1985: 2 broad approaches to coping - emotion-based & problem-based
- Folkman 1997 - 2000: meaning-based coping seen in carers of HIV patients
  - prominent contribution to positive affect states & development of resilience

Existential distress in Palliative Medicine

n = 162 terminally ill patients [Morita et al, 2000] Key dimensions explaining 67% of variance of distress:
- meaninglessness 37%
- hopelessness 37%
- dependency 39%
- fear of being a burden 34%
- role loss 29%

Diagnostic Criteria for Psychosomatic Research (DCPR) - Criteria for Demoralization

Fava, et al, 1995

1. Failed to meet expectations of self or others
2. Unable to cope with pressing problems
3. Feeling helpless, hopeless, giving up
4. Persisting mental state over past month
5. Mental state exacerbates physical disorder

Demoralization in the medically ill

Italian study of 129 patients post cardiac transplantation - Grandi et al
- N 41/129 (31%) had demoralization 2001
- 1/12 post transplant on this Bologna group’s DCPR - Diagnostic Criteria for Psychosomatic Research.
- Overlap with DSM-IV mood disorders: 10%
- Overlap with DSM-IV anxiety disorders: 30%
  - some co-morbidity exists !!

Diagnostic Criteria for Psychosomatic Research in 105 breast cancer patients

Grassi et al, 2004

- 30 patients (28.6%) met criteria for demoralization
- Demoralization was significantly associated with:
  - Hopelessness (Mini-MAC)
  - Depression (VAS)
  - Poor adjustment (VAS)
  - Cancer-related concerns (Cancer Worries Inventory)
  - Physical symptoms (VAS)
  - Poor leisure activity (VAS)
  - Poor social support (VAS)
  - Poor wellbeing (VAS)
Predictors of Suicide

Beck in 1975 found that hopelessness predicted suicide independently of depression.
- Wetzel et al, 1980: suicide intent in psychiatric inpatients correlated more strongly with hopelessness than depression.
- Dori et al, 1999: suicidal adolescents
- Gutkovich et al, 1999: primary care patients
- Breitbart et al, 1996: HIV patients
- Owen et al, 1994; Chochinov et al, 1998; Breitbart et al, 2000: cancer patients

Latent trait analysis of psychopathology in hospitalised physically ill

Clarke et al 1998

Using a validated, structured psychiatric interview developed for C-L Psychiatry, LT analysis was possible on a comprehensive symptom list. Five distinct dimensions were found:
1. anhedonic depression
2. anxiety states
3. somatic symptoms
4. grief
5. demoralization

Differentiating demoralization syndrome from depression I

- Core feature of depression: anhedonia, loss of pleasure or interest in life’s activities, both present & future.  
  [after Snaith 1987]
- Core feature of demoralization: meaninglessness / hopelessness, in which demoralized can enjoy consummatory pleasure, but lose anticipatory pleasure.  
  [after Klein 1980]

Differentiating demoralization syndrome from depression II

- Melancholic or endogenous depression: Motor change in facies, gesture, gait, speech  
  (after Parker et al)
- Demoralization: Interest is in the cognitive & affective, but without the motor aspects of melancholia.

Differentiating demoralization syndrome from depression III

- The demoralized can smile, laugh, demonstrate a broad range of reactive affects appropriate to the context.
- The demoralized can report activities that bring pleasure and a normal interest; thus not meeting DSM IV criteria for major depression.
- Co-morbid demoralization and depression
- Independent demoralization and depression

Differential diagnosis of Demoralization syndrome

- Adjustment disorder (with depressed mood)
- Major depressive episode
- Dysthymic disorder
- Substance-induced mood disorder
- Organic affective disorder [Mood disorder due to a general medical condition]
- Decathexis – Conservation withdrawal
Conservation withdrawal
Wallace Ironside, 1968

- Both a strategic retreat
- And an active means of coping
- Need is to CONSERVE energy
- While apparently avoidant, the motivation is not antisocially directed but protective of self.
- Bal Mount termed...decathexis

Case study of decathexis

- 56-yr old lawyer with advanced colon ca;
- Quiet, introverted, stoical guy
- Mild jaundice from early liver failure
- Can’t be bothered eating; denies nausea
- Fatigued, wants to sleep during day
- Complains that yesterday’s visitors stayed too long
- Asks if he can have a day without more visitors
- Is his social withdrawal maladaptive?

Demoralization scale
Kissane et al, 2004

Initially 34 items designed with subscales of:

**Non-specific dysphoria**
- eg. “I feel irritable” “I feel tense”

**Meaning & purpose**
- eg. “There is no purpose to the activities in my life” “My life seems to be pointless”

**Subjective incompetence**
- eg. “I cannot help myself” “I feel trapped.....

DEMORALIZATION SCALE
Kissane et al, 2004

- 1. Loss of meaning [5 items]
- 2. Dysphoria [5 items]
- 3. Disheartenment [6 items]
- 4. Helplessness [4 items]
- 5. Sense of failure [4 items]

All eigenvalues > 1 24 items
5 factor solution accounts for 67.1% of variance; alpha coefficients 0.79-0.89

DS FACTORS

**Dysphoria**
- Hurt
- Angry
- Guilty
- Irritable
- Regretful
- Loadings 0.752 – 0.632
- Alpha 0.85
- 16.0% variance

**Loss of meaning**
- Life not worth living
- Rather not be alive
- Pointlessness
- Loss of role
- Purposeless
- Loadings 0.832 – 0.575; α 0.87
- 16.1% variance

**Disheartenment**
- Distressed
- Discouraged
- Isolated/alone
- In good spirits (rev)
- Miserable
- Loadings 0.751 – 0.552
- α 0.89
- 14.6% variance

**Helplessness**
- Can’t be helped
- Feel helpless
- Not in control
- Hopelessness
- Loadings 0.808 – 0.547; α 0.84
- 10.9% variance
**DS FACTORS**

**Sense of failure**
- Proud of accomplishments (reversed)
- Lot of value in what I can offer (rev)
- Cope fairly well (rev)
- Worthwhile person (rev)

Loadings between 0.793 – 0.510
Alpha 0.71; 9.4% variance

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**Concurrent validity of DS**

Correlation co-efficients of:
- DS & McGill QoL (existential) = -0.756
- DS & Beck Hopelessness Scale = 0.668
- DS & HOPES = -0.648
- DS & SAHD = 0.577

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**Distinguishing Demoralization from DSM-IV Depression**

<table>
<thead>
<tr>
<th>PHQ &gt;10 used to define DSM-IV Major Depression</th>
<th>Total demoralization scale score split at median (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not depressed n = 61</td>
<td>Low DS 47 High DS 14</td>
</tr>
<tr>
<td>Depressed n = 39</td>
<td>Low DS 6 High DS 33</td>
</tr>
</tbody>
</table>

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**Distinguishing Demoralization from Depression**

<table>
<thead>
<tr>
<th>BDI-II category</th>
<th>Total demoralization scale score split at median (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal</td>
<td>Low DS 33 High DS 7</td>
</tr>
<tr>
<td>Mild</td>
<td>Low DS 15 High DS 13</td>
</tr>
<tr>
<td>Moderate</td>
<td>Low DS 5 High DS 14</td>
</tr>
<tr>
<td>Severe</td>
<td>Low DS 0 High DS 13</td>
</tr>
</tbody>
</table>

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**Demoralization, anhedonic depression & grief in patients with severe physical illness**

Clarke et al, World Psychiatry, 2005

N = 271 palliative care patients (134 Motor Neurone Disease, 137 Advanced Cancer) mean age 65 yrs; 41% female
Completed a structured psychiatric interview (MILP)

Principal components analysis: 3 factors
- Demoralization 13.2% of variance
- Anhedonic depression 8.3% of variance
- Somatic symptoms 6.8% of variance
Where loss acknowledged (gatekeeper Q): 1 further factor
- Grief 53% of variance

**Regression analyses for Demoralization & Anhedonia in patients with severe physical illness**

Clarke, Kissane, et al, 2005

- Demoralization
  - trait anxiety
  - younger age
  - use of resignation
  - use of avoidance
  - poor support
  - poor family cohesion
  [57% of variance]

- Anhedonia
  - trait anxiety
  - poor physical functioning
  - use of resignation
  - past psychiatric history
  [30% of variance]

Demoralization was significantly more prominent in MND, Anhedonia more prominent in cancer
### Comparison between Motor Neuron & Cancer

*Clarke et al, 2005*

- n = 134 motor neuron disease: 63 yrs, 62% male
- 55% ALS, 15% bulbar, 7% progr. muscular atrophy, 6% primary lat sclerosis
- Higher demoralization 24.3
- More suicidality 1.81
- Less anhedonia 11.6

- n = 137 advanced cancer: 67 yrs, 57% male
- 55% lung, 18% GI, 8% prostate, 7% breast, etc
- Demoralization 16.9 (p<0.001)
- Suicidality 0.46 (p=0.005)
- Anhedonia 14.1 (p=0.02)

### Comparison of motor neurone disease & metastatic cancer

*Clarke, Kissane et al, J Pall Care, 2005*

<table>
<thead>
<tr>
<th>Measure</th>
<th>MND (n=126)</th>
<th>Cancer (n=125)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>25.6</td>
<td>33.2 *</td>
<td>0.034</td>
</tr>
<tr>
<td>QLQ physical</td>
<td>30.5</td>
<td>43.2 *</td>
<td>0.0002</td>
</tr>
<tr>
<td>Demoralization</td>
<td>24.3 *</td>
<td>16.9</td>
<td>0.0001</td>
</tr>
<tr>
<td>Anhedonia</td>
<td>11.6</td>
<td>14.1 *</td>
<td>0.016</td>
</tr>
<tr>
<td>Grief</td>
<td>8.3 *</td>
<td>5.7</td>
<td>0.0000</td>
</tr>
<tr>
<td>Suicidal</td>
<td>1.8 *</td>
<td>0.5</td>
<td>0.0000</td>
</tr>
<tr>
<td>Resignation</td>
<td>8.8 *</td>
<td>7.6</td>
<td>0.0004</td>
</tr>
<tr>
<td>N close relatns</td>
<td>21.6</td>
<td>15.4 *</td>
<td>0.0000</td>
</tr>
</tbody>
</table>

### Demoralization in heroin addicts

*Cor de Jong et al, 2006*

<table>
<thead>
<tr>
<th></th>
<th>Community N = 190</th>
<th>Cancer N = 100</th>
<th>Opioid depend. N = 131</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td>37</td>
<td>59</td>
<td>42</td>
</tr>
<tr>
<td>MALE</td>
<td>35%</td>
<td>47%</td>
<td>85%</td>
</tr>
<tr>
<td>Length of illness</td>
<td>-</td>
<td>2.7 yrs</td>
<td>15 yrs</td>
</tr>
<tr>
<td>Total Dem S</td>
<td>21.1</td>
<td>30.8</td>
<td>43.2</td>
</tr>
</tbody>
</table>

**F = 77.65, P < 0.001**

### Treatment of demoralization in substance dependent pts

*Van den Nieuwenhuizen, et al., 2011*

<table>
<thead>
<tr>
<th>Week of treatment</th>
<th>Loss of meaning Mean (SD)</th>
<th>Disheartenment Mean (SD)</th>
<th>Total DS Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1</td>
<td>7.3(4.8)</td>
<td>12.8(4.6)</td>
<td>44.8 (15.4)</td>
</tr>
<tr>
<td>Week 5</td>
<td>5.8(4.2)</td>
<td>10.8(4.5)</td>
<td>40.4 (14.6)</td>
</tr>
<tr>
<td>Week 9</td>
<td>5.8(3.9)</td>
<td>10.4(3.8)</td>
<td>38.3 (13.1)</td>
</tr>
<tr>
<td>Week 13</td>
<td>4.7(3.9)</td>
<td>9.2(4.4)</td>
<td>34.9 (14.7)****</td>
</tr>
</tbody>
</table>

**Repetition measures analysis F = 14.56, p<0.001**

### German demoralization study

*Mehnert A et al, 2011*

- N=516 with advanced cancer
- Mean DS=29.8(SD10.4)
- Demoralization assoc Anxiety (r=0.71)
- Depression (r=0.61)
- Distress (r=0.42)

<table>
<thead>
<tr>
<th>Demoralization in Cohorts</th>
<th>n</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dutch Opioid addicted sample</td>
<td>124</td>
<td>43.2(17.1)</td>
</tr>
<tr>
<td>Australian outpatient palliative</td>
<td>101</td>
<td>30.8(17.7)</td>
</tr>
<tr>
<td>Australian Community sample</td>
<td>438</td>
<td>24.0(16.3)</td>
</tr>
<tr>
<td>Dutch Community sample</td>
<td>183</td>
<td>21.1(12.6)</td>
</tr>
<tr>
<td>Australian Early stage cancer</td>
<td>100</td>
<td>20.0(13.2)</td>
</tr>
<tr>
<td>Irish inpatient palliative care</td>
<td>100</td>
<td>19.9 (14.6)</td>
</tr>
<tr>
<td>US Early stage cancer</td>
<td>127</td>
<td>16.4(13.8)</td>
</tr>
</tbody>
</table>

### Sample divided 1SD above & below mean

<table>
<thead>
<tr>
<th>Sample divided 1SD above &amp; below mean</th>
<th>N=516</th>
<th>N=58</th>
<th>N=277</th>
<th>N=81</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ-9</td>
<td>No anxiety</td>
<td>N=306(60%)</td>
<td>N=190(30%)</td>
<td>N=60(12%)</td>
</tr>
<tr>
<td>GAD-7</td>
<td>No anxiety</td>
<td>N=365(69%)</td>
<td>N=214(42%)</td>
<td>N=65(13%)</td>
</tr>
<tr>
<td>Distress T</td>
<td>No distress</td>
<td>N=173(34%)</td>
<td>N=104(20%)</td>
<td>N=37(8%)</td>
</tr>
</tbody>
</table>
**Item Response Theory**

**Test Information Function: Full DI Scale**

**Distributions of Latent Demoralization Scores by Cohort**

**Standard Error of Measurement**

**Item Information Function: All DI Items**

**Item Information Curves: Loss Items**

**Item Information Curves: Dishearmament Items**
Item Information Curves: Helplessness Items

Demoralization Level

- di5 - I no longer feel emotionally in control
- di7 - No one can help me
- di8 - I feel that I cannot help myself
- di9 - I feel hopeless

Australian community sample
Clarke DM, Hayes L, Hawthorne G, Kissane DW
- Random telephone selection of 438 community-dwelling adults: mean 24.0 (SD 16.3), 95%CI 22.5-25.5
- Cronbach alpha = 0.96
- DS scores reduced with age; No effect of gender
- DS increases with poorer Global Health Rating
- DS increases with social isolation
- DS correlates strongly negatively with QoL
- DS correlates moderately negatively with Pleasure Scale
- DS correlates negatively with Snyder Hope scale

Demoralization norms by social isolation/connectedness

<table>
<thead>
<tr>
<th>Friendship scale quintile scores (social isolation)</th>
<th>Demoralization scale scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>Mean</td>
</tr>
<tr>
<td>---</td>
<td>------</td>
</tr>
<tr>
<td>Very isolated</td>
<td>38</td>
</tr>
<tr>
<td>Isolated</td>
<td>64</td>
</tr>
<tr>
<td>Some isolation/connected</td>
<td>72</td>
</tr>
<tr>
<td>Socially connected</td>
<td>103</td>
</tr>
<tr>
<td>Very connected</td>
<td>144</td>
</tr>
</tbody>
</table>

Total n = 421 Australian community sample

Demoralization by general health status, with effect sizes

<table>
<thead>
<tr>
<th>Health status</th>
<th>N</th>
<th>Mean (SD)</th>
<th>95% CI</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>61</td>
<td>13.3(9.7)</td>
<td>10.9-15.7</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>162</td>
<td>19.3(12.7)</td>
<td>17.8-20.8</td>
<td>0.53</td>
</tr>
<tr>
<td>Good</td>
<td>135</td>
<td>28.8(15.7)</td>
<td>27.7-31.9</td>
<td>1.19</td>
</tr>
<tr>
<td>Fair or poor</td>
<td>57</td>
<td>37.5(20.1)</td>
<td>32.3-42.7</td>
<td>1.53</td>
</tr>
</tbody>
</table>

N = 415, Australian community sample, F = 19.58 df = 4, 412; p<0.01

Distinguishing Demoralization from Depression

<table>
<thead>
<tr>
<th>BDI-II category</th>
<th>Split Demoralization Scale score (palliative care, n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low DS</td>
</tr>
<tr>
<td>Minimal</td>
<td>33%</td>
</tr>
<tr>
<td>Mild</td>
<td>15%</td>
</tr>
<tr>
<td>Moderate</td>
<td>5%</td>
</tr>
<tr>
<td>Severe</td>
<td>0</td>
</tr>
</tbody>
</table>

Clinical associations of demoralization syndrome

- younger age
- bodily disfigurement
- physical disability
- mental disability
- dependency on others & concern about being a burden
- suicidality

- No effect of gender
- social isolation
- perception or fear of loss of dignity
- being a carer
- co-morbid depressive or anxiety disorders
- medically ill
**Construct validity - Demoralization**

How we understand its development:
- **Protecting:** FH genetics; resilience; strength of character; secure attachments; religious & philosophical convictions
- **Predisposing:** PH of childhood/family nurturance of self worth; life events/losses; medical illness
- **Precipitating:** Change in hope & meaning of life; prognosis; treatments
- **Perpetuating:** Physical symptom control; relational support; family dysfunction; clinician’s attitudes – countertransference

**Predictive validity of Demoralization syndrome**

The course & treatment outcome are important aspects of syndromal validity:

**Course of an untreated Demoralization**
chronic distress, major depression, social withdrawal, suicidal urge, poorer physical wellbeing, search for death

**Treatment options for Demoralization Syndrome**

1. Continuity & active symptom management – antidepressants if comorbidity
2. Explore attitudes to hope & meaning in life, narrative & dignity therapies: review life’s story
3. Balance support for grief with promotion of hope & discussion of transitions: Inter Personal Therapy
4. Foster search for renewed purpose & role in life: IPT, meaning-centered therapies

**Narrative review of life story**

- Developmental history
- Cassell: an unique life lived is a work of art
- Gaita: value each person as inherently precious because of our common humanity

**LIFE NARRATIVES**

- **AIM** to understand each person’s philosophy of life and the meaning they therefore understand their life to hold.
- Help them to construct this meaning if they struggle to do alone.

**Change - Role transition -I**

- Role changes often involve LOSSES
- Need to mourn the loss of the old to facilitate acceptance of the new
- Dispute negative attitudes to new role
- Promote self esteem through mastery over new role
CHANGE - Role transition -II
- Explore emotional dimensions of any change, identifying the link of any symptoms to this transition
- Review old role positively & negatively
- Review new role positively & negatively
- Identify any challenges that seem too great
- Construct approaches to deal with these challenges

Restoring hope & meaning
- Dufault & Martocchio 1985: generalised hope rescues when particular hopes seem lost.
- Set goals - activity scheduling
- Hypothetical - what if?
- Examine roles in life - not just career, but in family - with others.
- What tasks remain with family members?
- Can benefit for others be identified in the sick role?

Breitbart’s Meaning-centered Groups based on Frankl’s logotherapy
1. Concepts of meaning and sources of meaning;
2. Cancer and meaning, meaning and historical context of life;
3. Storytelling and narrative life project;
4. Limitations and finiteness of life;
5. Responsibility, creativity and deeds;
6. Experience of nature, art, humor;
7. Goodbyes and hopes for the future.

Understanding the person
Cassem, 2000
- Who & who at the top of their game?
- Accomplishments, positive, naughty
- Passions, favourites, addictions
- Family, friends & enemies
- Explore with family whenever possible
- Defines the self esteem & character of the person

Treatment options for Demoralization Syndrome - II
5. Promote supportive relationships & use of community volunteers
6. Use cognitive therapy to reframe negative beliefs
7. Conduct family meetings to enhance family functioning
8. Review goals of care in multidisciplinary team meetings

CBT in Demoralization
- THINKING ERRORS:
  - pessimism
  - magnification
  - specific focus on the negative
  - self labelling
- Acknowledge regret but counter guilt - identify unrealistic expectations.
- Promote the reality of a ‘goodness that is sufficient.’
- Explore ‘being’ rather than ‘doing’.
Existential postures of vulnerability & resilience

Vulnerability
1. Confusion
2. Isolation
3. Despair
4. Helplessness
5. Meaninglessness
6. Cowardice
7. Resentment
8. Fear of unknown

Resilience
1. Coherence
2. Togetherness
3. Hope
4. Control & Agency
5. Purpose
6. Courage
7. Gratitude
8. Reverence

Examining philosophy of life - I

- What sort of person have you been?
- How would you like to be remembered?
- How would you describe your disposition? Temperament?
- Who are the most important persons to you?
- Anyone whose needs you would put ahead of your own?
- Has there been a set of values you’ve lived by?

Examining life’s philosophy - II

- What are (have been) your goals?
- What are you especially proud of?
- Is there anything worth dying for?
- Anything you want to finish, improve, resolve?

- So how would you describe your yourself and your life?

SEARCH for MEANING

- What has mattered most in your life?
- What matters now? Any goals?
- Has there been a sense of continuity, a theme that describes what your life has been about? A mission?
- What gifts can you give? Can you leave?
- How do you learn to live ill? Disabled? Disfigured?
- Could you prepare your loved ones to live with you changed? How?

Is there meaning in death?

- Religious:
  - transcendent belief: rebirth or transition to heaven

- Agnostic - atheist:
  - humanist view of cycling of nature; transmission to next generation

- Spiritual:
  - sense of universal journey
  - meaning of life
  - dignity in dying
  - adaptive mourning

HOPE and CHANGE

The importance of transition:

- Hope for more time, quality, pleasure
- Hope that I can learn to live ill
- Hope that my survivors will benefit

Reality-based honesty, genuineness of interest, nurture creativity despite mourning
Questions that deepen generalised hope

• Dare you hope for improved quality of life? Can you hope to learn to live ill?
• Dare you hope for rebirth? For passage to a continued spiritual existence? For God?
• Do you recognise an inner hope that transcends the ordinary particular hopes in life?
• Can you hope that your survivors benefit?

Perceiving your role despite sickness - I

• What is your unfinished business?
• Who matters to you?
• What conversations do you want to have?
• Can you talk about leaving? Dying?

Perceiving your role despite sickness - II

• Can you prepare your children / grandchildren about death?
• Who will profit from your affirmation?
• What gifts can you leave?
• How will you go about saying thanks?

Understanding the transition

• How is your illness (dying) consistent with your life story?
• Can anything creative/worthwhile come out of your illness?
• Is the journey as frightening as the expectation?
• What’s the saddest aspect of the change?
• How have you coped with other change?
• Will there be a time when you might be ready to die?

Acceptance of dying

The current Western ethos of the ‘heroic death’, in which awareness of dying is faced with courage, is achieved by many [Seale 1995]. Their mental attitude of acceptance can be expressed as:
• “I’m ready to die”
• “When my time comes”
There is no desperation to die.
• Acceptance of dying is very possible without demoralization

‘Burn out’ in oncology

• Progressive loss of idealism, energy & purpose in clinical practice, leading to exhaustion, dissatisfaction, negative attitudes to patients and to self

[Edelwich, 1980; Maslach, 1982; Vachon, 2000]

• The demoralized doctor
**COUNTERTRANSFERENCE**

*Boundary issues in doctor-patient relationship:*

Comparison between boundary violations in having sex with a patient & killing a patient. [Gabbard 1995; Varghese & Kelly 1999]

Countertransference ‘hate’ versus countertransference ‘undignified’ / ‘unworthy’ of life / pity or compassion / helplessness / pointlessness incl. resources

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**Clinical correlates of the wish to hasten death**  
Kelly et al, 2002

- 256 patients & 252 doctors were independently surveyed on referral to palliative care
- 15% of patients indicated a persistent wish to hasten death (WTHD).

Predictors of patient’s WTHD included:
1) doctor’s willingness to hasten death;
2) doctor’s sense of pessimism & distress in patient; and
3) doctor’s reduced experience/training in psychological care.

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**Demoralization in the multidisciplinary team**

- Dignity challenged by a sense of revulsion or disgust at bodily decay: rotting bed sores, foul odour, incontinence, agitated confusion, disfigurement
- Loss of continuity of care
- Loss of leadership, compounded by rigidity of processes, polarisation of views
- Burnt out staff, carrying attitudes of pointlessness, hopelessness & worthlessness towards pts & fs

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**Demoralization in families**

- Distress at poorly controlled symptoms
- Sense of helplessness at the existential plight of their relative
- Perception of loss of dignity
- Strain of care provision, burden
- Negative perception of the future
- More intense with less family cohesion and poorer family functioning