DEMORALIZATION and EXISTENTIAL DISTRESS IN ONCOLOGY

David W Kissane MB BS, MPM, MD, FRANZCP, FRACGP, FAChPM.
Professor of Psychiatry, Cornell University;
Jimmie C. Holland Chair, Attending Psychiatrist & Chairman, Department of Psychiatry & Behavioral Sciences,
Memorial Sloan-Kettering Cancer Center,
New York, NY, USA

non-caring attitudes to life

Disorders of <u>meaning</u>:	Disorders of <u>affect</u>:
▪ existential despair	▪ unhappiness
▪ spiritual torpor	▪ depression
▪ mopishness	▪ hopelessness
▪ pointlessness	▪ helplessness
▪ acedia	▪ anxiety
▪ demoralization	▪ 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

Kissane DW, Treece C, et al, 2009

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

What are these major existential challenges?

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

Kissane et al, 1997; Kissane DW 2000; Kissane & Poppito 2006; Kissane et al, 2009

Forms of existential distress

1. Death	• Death anxiety
2. Loss	• Complicated grief
3. Freedom	• Loss of control
4. Dignity	• Worthlessness
5. Aloneness	• Profound loneliness
6. Relationships	• Conflict & alienation
7. Meaninglessness	• Demoralization
8. Mystery	• 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 6. Alienation	• Dysfunctional family, relationship problems
7. Demoralization	• Demoralization syndrome, Depression
8. Spiritual doubt & despair	• Adjustment disorders

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

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

Dimensional NATURE of DEMORALIZATION

Change in morale spans a spectrum of mental states:

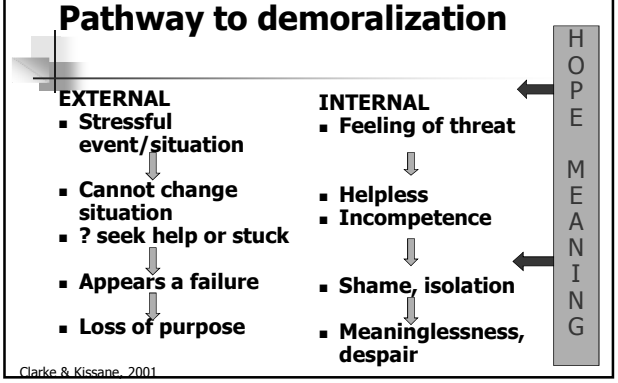
- Disheartenment [mild loss of confidence]
- Despondency [starting to lose hope]
- Despair [lost hope]
- Demoralization [lost purpose & given up]

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



Clarke & Kissane, 2001

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 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
- Schmale 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 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 2001

- **N 41/129 (31%) had demoralization 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 <u>decathexis</u>

- **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:

<u>Non-specific dysphoria</u>

eg. "I feel irritable" "I feel tense"

<u>Meaning & purpose</u>

eg. "There is no purpose to the activities in my life" "My life seems to be pointless"

<u>Subjective incompetence</u>

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

<u>Dysphoria</u>

- **Hurt**
- **Angry**
- **Guilty**
- **Irritable**
- **Regretful**
- **Loadings 0.752 – 0.632**

Alpha 0.85
16.0% variance

<u>Loss of meaning</u>

- **Life not worth living**
- **Rather not be alive**
- **Pointlessness**
- **Loss of role**
- **Purposeless**

Loadings 0.832 – 0.575; α 0.87
16.1% variance

DS FACTORS

<u>Disheartenment</u>

- **Distressed**
- **Feel trapped**
- **Discouraged**
- **Isolated/alone**
- **In good spirits (rev)**
- **Miserable**

Loadings 0.711 – 0.552
Alpha 0.89
14.6% variance

<u>Helplessness</u>

- **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

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

Distinguishing Demoralization from DSM-IV Depression

PHQ >10 used to define DSM-IV Major Depression	Total demoralization scale score split at median (n=100)	
	Low DS	High DS
Not depressed n = 61	47	14
Depressed n = 39	6	33

Distinguishing Demoralization from Depression

BDI-II category	Total demoralization scale score split at median (n=100)	
	Low DS	High DS
Minimal	33	7
Mild	15	13
Moderate	5	14
Severe	0	13

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
- 31% 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

Measure	MND (n126)	Cancer (n125)	P-value
Pain	25.6	33.2 *	0.034
QLQ physical	30.5	43.2 *	0.0002
Demoralization	24.3 *	16.9	0.0001
Anhedonia	11.6	14.1 *	0.016
Grief	8.3 *	5.7	0.0000
Suicidal	1.8 *	0.5	0.0000
Resignation	8.8 *	7.6	0.0004
N close relatns	21.6	15.4 *	0.0000

Demoralization in heroin addicts

Cor de Jong et al, 2006

	Community N = 190	Cancer N =100	Opioid depend. N = 131
AGE	37	59	42
MALE	35%	47%	85%
Length of illness	-	2.7 yrs	15 yrs
Total Dem S	21.1	30.8	43.2
	F = 77.65, P < 0.001		

Treatment of demoralization in substance dependent pts

Van den Nieuwenhuizen, et al., 2011

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

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

DEMORALIZATION – a morbid state with loss of meaning predominating

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

German demoralization study

Mehnert A et al, 2011

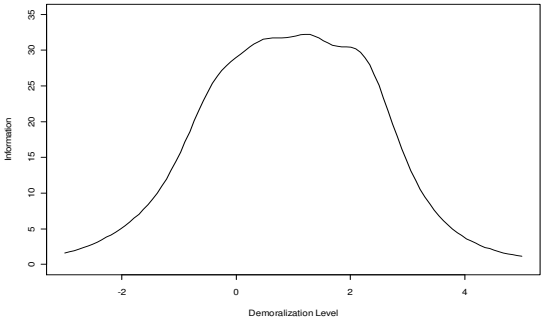
- N=516 with advanced cancer
- Mean DS=29.8(SD10.4)

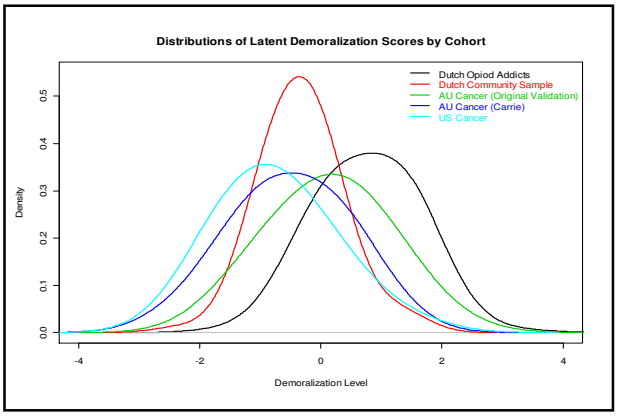
- Demoralization assoc
Anxiety (r=0.71)
Depression (r=0.61)
Distress (r=0.42)

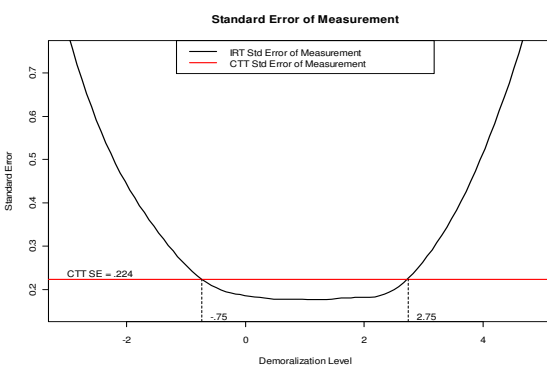
Sample divided 1SD above & below mean

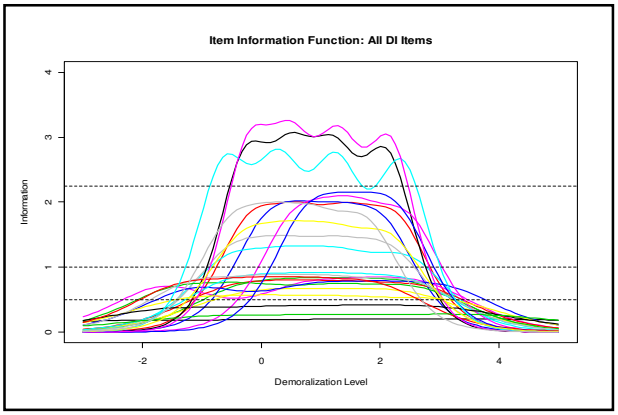
N=516	Low DS (<19) N=58	Moderate DS (19-40) N=377	High DS (>40) N=81
PHQ-9			
No depress	57(11%)	308(60%)	**26 (5%)**
Depressed	1(0.2%)	69(13%)	55 (11%)
GAD-7			
No anxiety	58(11%)	356(69%)	**44 (8.5%)**
Anxious	0	21(4%)	37 (7%)
Distress T			
No distress	39(7.5%)	173(34%)	9 (2%)
Distress	19(4%)	204(40%)	72 (14%)

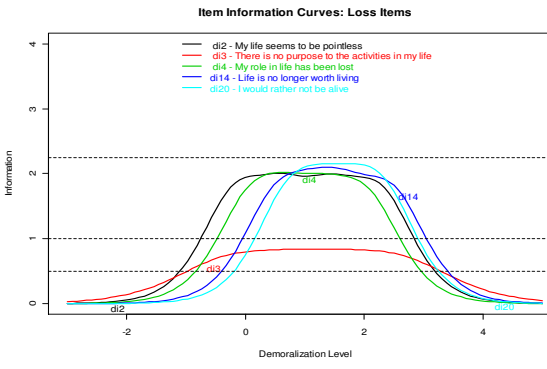
Item Response Theory

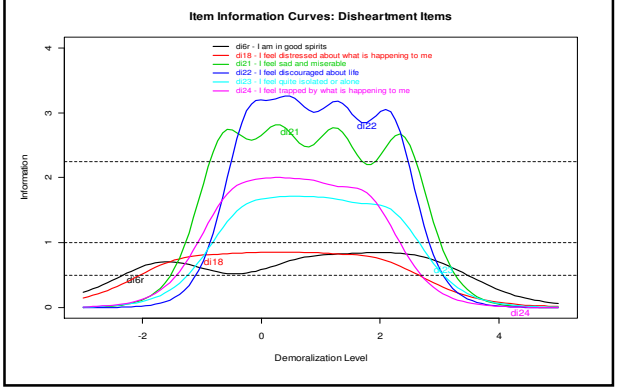


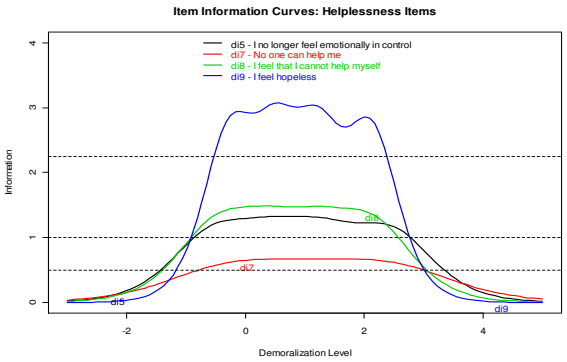












Australian community sample

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

Friendship scale quintile scores (social isolation)	Demoralization scale scores			
	n	Mean	SD	95% CI
Very isolated	38	49.3	17.3	43.8-55.8
Isolated	64	37.0	13.8	33.6-40.4
Some isolation/connected	72	26.8	10.9	24.3-29.3
Socially connected	103	19.9	11.6	17.8-22.0
Very connected	144	13.3	9.7	11.7-14.9

Total n = 421 Australian community sample

Demoralization by general health status, with effect sizes

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

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

Distinguishing Demoralization from Depression

BDI-II category	Split Demoralization Scale score (palliative care, n=100)	
	Low DS	High DS
Minimal	33%	7%
Mild	15%	13%
Moderate	5%	14%
Severe	0	13%

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 I

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.

Breitbart W, 2002

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	Resilience
1. Confusion	1. Coherence
2. Isolation	2. Togetherness
3. Despair	3. Hope
4. Helplessness	4. Control & Agency
5. Meaninglessness	5. Purpose
6. Cowardice	6. Courage
7. Resentment	7. Gratitude
8. Fear of unknown	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 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

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.**

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**

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**