Demoralization in patients with cancer

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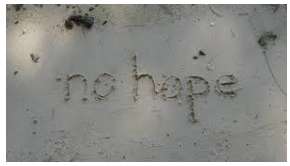
Definition

- **Demoralization** – **a mental state of lowered morale and poor coping**, characterized by feelings of hopelessness, helplessness, and loss of meaning and purpose in life.

(Kissane, Clarke, & Street, J Palliative Care, 2001; Kissane, J Palliative Care, 2014)



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In this lecture…

1. **Review concept of demoralization**
2. **Systematic review of literature**
3. **Recent work on measurement**
4. **Fitting it into the diagnostic system**
5. **How to treat demoralization**

Acknowledgements:
Bethlehem Griffiths Foundation & Monash University

Sophie Robinson, Courtney Hempton, Peter Gaitanis
Michael Franco, Natasha Michael, Merlina Sulistio, Jane Fischer
Julie Pallant, Joanne Brooker, Mehmet Ozmen

Background

Bramley, Tate Gallery

- **The construct of demoralization**

The morale continuum

- Mild loss of confidence
  - Disheartenment
- Beginning to lose hope & purpose
  - Doubt
  - Despondent
- Hope & meaning are lost
  - Despair
  - Demoralisation

- **Dimensional**
- **Pathological when severe**

Old concept reactivated

- **Victor Frankl (1959, 1963) "Suffering itself does not destroy man, rather suffering without meaning"**
- **Engel (1967): 'giving up - given up' complex**
- **Gruenberg (1967): 'social breakdown syndrome' with institutionalisation of chronically mentally ill**
- **Jerome Frank (1968, 1974): hope & the restoration of morale in psychotherapy**
- **Seligman (1975): 'learned helplessness'**

Frankl

Engel

Frank

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

  - meaning makes a prominent contribution to positive affect states & development of resilience

Meaning has been broadly neglected by psychiatry, yet is central to concepts of existential distress

Criteria for Demoralization

Persisting mental state over two or more weeks as a result of a stressor event, with features of:

A. Lowered morale & resultant distress
B. Difficulty in coping & meeting expectations of self or others
C. 3 (or more) of following symptoms:
   1. Meaninglessness
   2. Hopelessness or helplessness, sense of stuckness
   3. Loss of purpose, pointlessness of future
   4. Reduced self-worth & sense of failure
   5. Desire for hastened death
   6. Suicidal thoughts &/or plans

D. Level of low morale & poor coping cause significant distress or impairment in social, occupational or other functioning

Systematic review of demoralization

Robinson, Kissane et al JPSM 2015

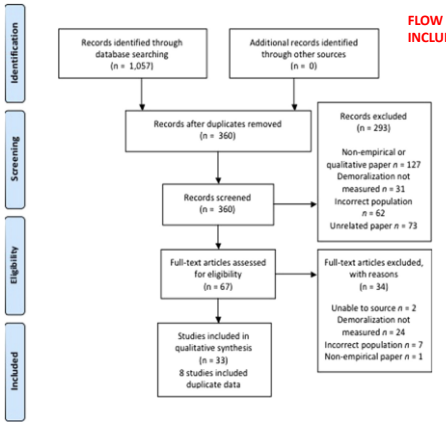
- PRISMA guidelines: Preferred reporting guidelines for systematic reviews and meta-analyses. [Moher et al, 2009]

- 9 databases: PsycINFO, PubMed, Ovid Medline, CINAHL, EMBASE, Scopus, Cochrane, Informit & Web of Sciences.

- Keywords: cancer OR palliative AND demorali* OR meaning* OR hopeless* OR helpless*

- Searched on 16th August 2013

Robinson, S., Kissane, D. W., Brooker, J., & Burney, S. (2015). A systematic review of the demoralization syndrome in individuals with progressive disease and cancer: a decade of research. *Journal of pain and symptom management, 49(3), 595-610.*



FLOW DIAGRAM OF INCLUDED STUDIES

Table 2: Threshold for the Clinical Presence of Demoralization with the DS

Source	M(SD)	M+1SD	Prevalence Clinically Significant
Boscaglia & Clarke (2007) / Clarke (2011) / Clarke & Boscaglia (2011)	22.2 (16.8)	38.9	18%
Costantini et al. (2013)	23.9 (14.5)	38.4	14%
Fang et al. (2012)	28.8 (12.6)	41.4	NR
Hadnagy et al. (2012)	61.3 (12.4)	73.7	NR
Hung et al. (2010) / Lee et al. (2012)	31.1 (14.9)	45.9	NR
Kissane, Wein, et al. (2004)	30.8 (17.7)	48.6	18%
Mehnert et al. (2011a/2011b)	29.8 (10.4)	40.2	16%
Mullane et al. (2009)	19.9 (14.6)	34.6	13%
Vehling et al. (2011/2012)	22.2 (13.9)	36.1	15.5%

25 studies

4,545 patients

Prevalence 13-18%

Comparison of measures of demoralization

Diagnostic Criteria for Psychosomatic Research (DCPR) [Fava et al, 1995]

- Categorical
- Structured interview
- 5 items
- Time frame: 1 month
- Mental state may precede illness

- **Prevalence of demoralization: 21-33%**

Demoralization Scale (DS) [Kissane et al, 2004]

- Dimensional
- Self-report measure
- 24 items
- Time frame: 2 weeks

- **Prevalence of demoralization: 13-18%**

Source	Country	Factor structure	Internal Reliability		Convergent validity	Divergent Validity
			Total	Subscales		
Demoralization Scale Validation studies						
Costantini et al. (2013)	Italy	Loss of meaning and purpose; dysphoria; disheartenment; helplessness; sense of failure	.90	.50 - .84	BDI; MAC	**6-20%** high demoralization but no clinical depression
Kissane et al. (2004)	Australia	Loss of meaning and purpose; dysphoria; disheartenment; helplessness; sense of failure	.94	.71 - .89	McGill QOL; PHQ; BDI; BHS; HOPES; SAHD	**7-14%** high demoralization but no clinical depression
Hung et al. (2010)	Taiwan	NR	.93	.63 - .85	BHS, McGill QOL	**23.4%** high demoralization but no clinical depression
Mehnert et al. (2011)	Germany	Loss of meaning and purpose; dysphoria; disheartenment; sense of failure	.84	.76 - .88	DT; PHQ; GAD-7; LAP-R	**5% - 20%** high demoralization but no clinical depression
Mullane et al. (2009)	Ireland	Loss of meaning and purpose; dysphoria; disheartenment; helplessness; sense of failure	.93	.72 - .86	BDI; PHQ; BHS; SAHD; McGill QOL; HOPES	**2.1% - 5.2%** high demoralization but no clinical depression

Quality ratings of studies of demoralization - I

SOURCE	COUNTRY	Cohort Size	Quality rating
Boscaglia & Clarke 2007; 2011	Australia	120 gynecol ca	.80
Clarke…Kissane 2005	Australia	251 MND v Ca	.85
Cockram…DeFigueiredo 2009	USA	112 ca	.70
Cockram et al 2010	USA	71 ca	.80
Grandi et al, 2011	Italy	95 heart	.80
Grassi et al, 2004; 2005	Italy	146 ca	.85
Lee et al, 2012	Taiwan	234 ca	.90
Jacobsen et al, 2006	USA	242 adv ca	.85
Katz et al, 2001	USA	118 ca + lupus	.80
Kissane et al 2012	USA	104 H&N ca	.80

Quality ratings of studies of demoralization - II

SOURCE	COUNTRY	Cohort Size	Quality rating
Kissane et al, 2004	Australia	100 adv ca	.90
Mangelli et al, 2005	Italy	351 heart	.75
Rafanelli et al, 2013	Italy	351 heart/Infarct	.85
Sirri et al, 2012	Italy	100 ca	.95
Mehnert et al, 2011	Germany	516 adv ca	.90
Morita et al, 2000	Japan	162 hospice pts	.80
Mullane et al, 2009	Ireland	100 adv ca	.75
Passik et al, 2003	USA	100 ca	.80
Rafanelli et al, 2009	Italy	68 CCF	.80
Sautier et al, 2014	Germany	112 ca	.85
Vehling et al, 2011,2012	Germany	270 ca	.90
Vehling et al, 2013	Germany	750 ca	.95

Predictors of demoralization

Positive associations (more demoralization)

- Being single, separated, divorced, living alone
- Reduced social support (n=1,153)
- Gender - Women (n=1,631)
- Physical symptom burden (n=1,788)
- Mental symptom burden [depressed (n=2,372), anxious (n=968), suicidal (n=442), distress (n=602)]

Negative associations (less demoralization)

- Being married (n=725)
- Being employed (n=321)
- Being religious or spiritual
- Activity / exercise (n=233)
- Good quality of life (n=675)
- Hopefulness (n=200)
- Purpose in life (n=611)

What is not associated with demoralization thus far:

Coping factors (mostly single studies to date)

Positive links likely to: self-blame, denial, social withdrawal, non-acceptance, shame, dependence, high stress, somatization, poor disease controllability & cancer concerns.

Protective factors: autonomy, sense of mastery, coherence, inner peace, global meaning, type A behaviour, social support

Unrelated to demoralization:

Age mostly unrelated (n=1266)

Level of education, Type of religion,

Time since diagnosis (n=723), stage of disease (n=770), type of treatment (n=650), cancer site

Differentiation of demoralization from depression – divergent validity

High demoralization & not major depression

- Lee et al, 2012: 27.4%
- Hung et al, 2010: 23.4%
- Hadnagy et al, 2012: 10.5%
- Kissane et al, 2004: 7-14%
- Costantini et al, 2013: 6-20%
- Mehnert et al, 2011: 5-20%
- Jacobsen et al, 2006: only 15% of those demoralized met criteria for major depression

No difference between demoralization & depression

- Mullane et al, 2009 – high use of religion in Irish sample: 2.1 – 5.2% had high demoralization yet not depressed

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%)

Cross-tabulation frequencies (n=194 Italian cancer patients) between the categories of demoralization and the presence of PHQ-9 depression 'caseness'

PHQ-9 case vs non-case	DS Category			
	No (n=43) 22%	Low (n=104) 53%	Moderate (n=14) 7%	High (n=33) 17%
	< mean +1SD	25th to 75th percentile	75th percentile to Mean +1SD	> Mean +1SD
Non-Case (≤9)				
% of total	21.6%	43.8%	5.7%	8.2%
Count	42 (97.7%)	85 (81.7%)	11 (78.6%)	16 (48.5%)
Expected count	34.1	82.6	11.1	26.2
Case (≥10)				
% of total	0.5%	9.8%	1.5%	8.8%
Count	1 (2.3%)	19 (18.3%)	3 (21.4%)	17 (42.5%)
Expected count	8.9	21.4	2.9	6.8
χ^2 28.5, df 3, p=0.0001				

About 50% of those who were highly demoralized were not depressed, and about 80% of those who were moderately demoralized were not depressed on the PHQ-9.
Grassi et al, 2017, Psycho-Oncology

Demoralization systematic review

Tecuta ….Fava, Psych Med 2015

DCPR criteria for Demoralization

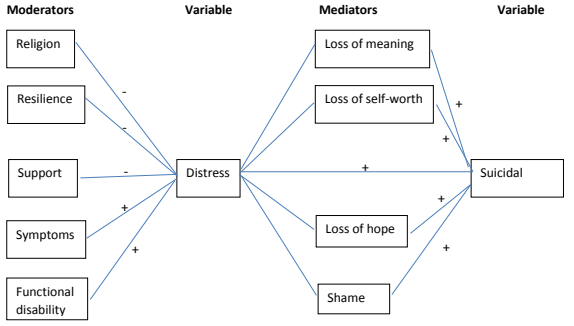
1. The patient feels as if they have failed to meet the expectations set by themselves or those around them or experiences a general inability to cope with demands. This results in feelings of helplessness, hopelessness, and a desire to give up.
2. The feelings are prolonged, generalized, and are present for at least 1 month.
3. The feelings directly precede the development of a medical disorder or strengthen its symptoms.

Note: doesn't have loss of meaning as a criterion

Prevalence rates

- **Community prevalence using DCPR: 3%**
- **Psychiatric populations: 50%**
- **Medically ill populations: 30%**
  - **Cardiac, hypertension, cancer, primary care, endocrine, dermatology**

Model of Correlates of Desire for Death

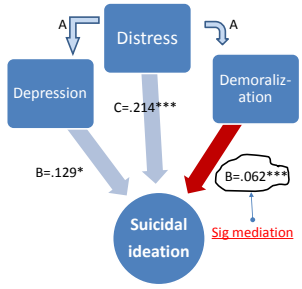


Predictors of suicidal ideation

Fang CK, et al, Support Care Cancer 2014

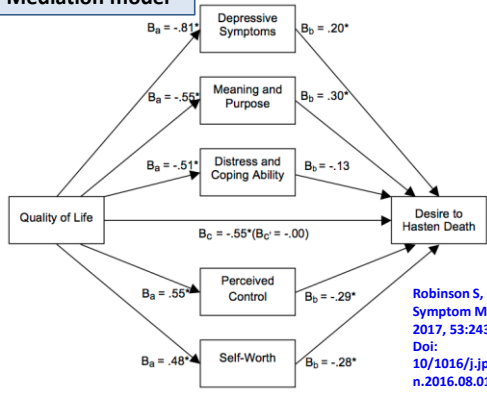
Regression analyses of predictors of suicidal ideation

Variable	t	P-value
Never married	2.78**	0.005
Depression	0.38	0.701
Demoralization	2.84**	0.005
Loss of meaning	2.54**	0.011



*p<.05
***p<.001

Mediation model



Robinson S, et al. J Pain Symptom Management 2017, 53:243-249. Doi: 10/1016/j.jpainsymman.2016.08.013

Association of demoralization and self-reported depression with Relative Risk for CIDI-O mental disorders and suicidal ideation

Model	Any mood disorder (n=430) RR	95% CI	Any anxiety disorder (n=430) RR	95% CI	Suicidal ideation without mood or anxiety dis (n=370) RR	95% CI
1. Demoralization	7.8***	3.4 to 17.9	3.7***	2.2 to 6.1	2.8*	1.2 to 6.7
2. Depression	7.7***	3.2 to 18.8	2.3***	1.4 to 3.8	1.4	0.6 to 3.3
3. Demoralization	4.0*	1.3 to 12.1	3.3***	1.8 to 5.8	3.1*	1.3 to 7.7
Depression	3.7*	1.1 to 12.1	1.3	0.7 to 2.3	0.8	0.3 to 2.0

Vehling, S et al., in Cancer, 2017, Revision under review

Clinical implications

- **Moderate Demoralization Syndrome** is consistent with DSM-5 Adjustment Disorder. Is it better named **Adjustment Disorder with Demoralization**?
  - Treat with psychotherapy

With a prevalence of about 15%, Demoralization is common

- **Severe Demoralization Syndrome**
  - May occur alone or be co-morbid with depression
  - If co-morbid with major depression, treat with Antidepressants & psychotherapy
  - If occurs alone, treat with psychotherapy
  - Is this better named **Major Depression with demoralization?**

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Medicine, Nursing and Health Sciences

Refinement and Revalidation of the Demoralization Scale

Published in *Cancer 2016*

Sophie Robinson, David W Kissane, Joanne Brooker, Natasha Michael, Jane Fischer, Michael Franco, Courtney Hempton, Merlina Suslistio, Julie Pallant, David Clarke, Mehmet Osmen and Sue Burney

Rationale for DS measure refinement

- Rasch analysis identified 5 **underperforming items** on the Demoralization Scale
  - Reversed items may lead to confusion in respondents
- A revised version of the DS has been created with these 5 items reworded so that all 24 items have the same valence
  - E.g., "There is a lot of value in what I can offer others" became "There is little value in what I can offer others"

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Item Response Theory - Rasch Analysis

- IRT represents a family of techniques, including Rasch analysis, that use mathematical models to **examine the performance of each item and each person** in a scale.
- **In the Rasch model we examine:**
  - **Unidimensionality**
  - **Category ordering of Likert responses**
    - **Do the response option categories work as expected?**
  - **Item bias (differential item functioning)**
    - **Do different groups (e.g., males/females) with the same level of demoralisation respond differently to any items?**
- Rasch analysis may also help to **shorten a scale**, as it provides information about items that overlap in difficulty level.

(Pallant & Tennant, 2007)

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Method

Design

- **Multi-site; observational; quantitative study**
- Longitudinal aspect for test-retest reliability, repeat 1 week later

Participants

- 211 palliative care patients: Patients were recruited from Cabrini Palliative Care (n=90), Calvary Health Care Bethlehem (n=77), and Monash Health (n=44) between June 2013 – November 2014
  - Eligibility criteria:
    - Inclusion: advanced progressive disease, no intellectual impairment, and English-speaking
    - Exclusion: Too unwell to consent

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Results – Sample Characteristics

Mean age (years):
70.98 (*SD* 12.00)

N=211

77% recruitment rate

Variable	n	%
Sex		
Male	109	51.7
Female	102	48.3
Marital Status		
Single/Divorced/Widowed	98	53.6
Married/De Facto	113	46.4
Education		
Secondary (incomplete/complete)	96	45.5
Trade / College training	51	24.4
Tertiary	62	29.7
Primary Diagnosis		
Advanced cancer	189	89.6
Cardiac/Neurological/Respiratory/Renal	22	10.4

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Principal Components Analysis

	Component 1	Component 2	
Item 02: *Life pointless*	**.83**	-.05	Meaning and Purpose
Item 14: *No longer worth living*	**.80**	-.01	
Item 03: *No purpose in life*	**.80**	-.09	
Item 20: *Rather not be alive*	**.74**	-.14	
Item 01: *Little value to offer others*	**.63**	-.06	
Item 04: *Role in life lost*	**.61**	.13	
Item 08: *Cannot help myself*	**.55**	.16	
Item 07: *No one can help*	**.55**	.20	
Item 22: *Discouraged about life*	**.51**	.31	
Item 09: *Hopeless*	**.50**	.34	
Item 19: *Not worthwhile person*	**.47**	.15	
✖ Item 06: *Not in good spirits*	.40	.39	
Item 11: *Irritable*	-.25	**.77**	Distress and Coping Ability
Item 15: *Hurt easily*	-.12	**.75**	
Item 16: *Angry about things*	-.06	**.75**	
Item 18: *Distressed about what is happening*	.08	**.68**	
Item 24: *Trapped by what is happening*	.20	**.57**	
Item 21: *Sad and miserable*	.26	**.57**	
Item 10: *Guilty*	.00	**.53**	
Item 12: *Do not cope well*	.27	**.51**	
Item 13: *Regret about life*	.14	**.48**	
Item 05: *No longer emotionally in control*	.24	**.48**	
Item 23: *Isolated or alone*	.24	**.46**	
✖ Item 17: *Ashamed of little accomplished*	.24	.33	

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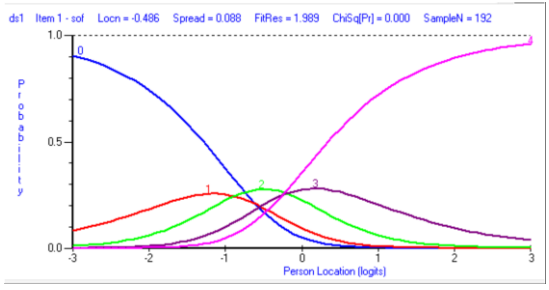
Disordered item thresholds – 5 Likert response options



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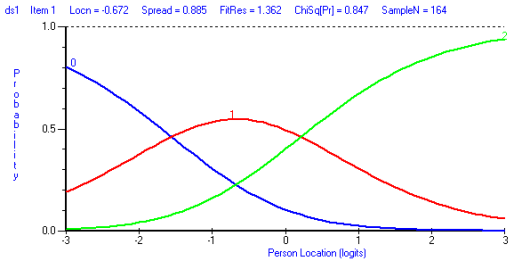
After collapsing to 3 response options

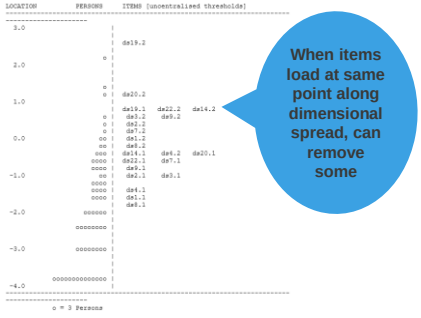


Results – Rasch Modeling – RUMM2030

- Separate Rasch modeling of each component resulted in collapsing the number of response option categories from 5 to 3

- This was consistent with the researchers' observations during the scale administrations
  - Participants showed inconsistent use of the options "seldom/sometimes" and "often/all the time"

Results - Rasch modelling – item removal



When items load at same point along dimensional spread, can remove some

Results – Rasch Modeling

Scale	Analysis	Overall model fit	Item fit residual mean (SD)	Person fit residual mean (SD)	% sig	Internal consistency	
					t-tests	PSI	α
Meaning and Purpose							
11-items	1	$X^2 = 39.75$, $p = .01$	.13 (1.20)	.27 (1.07)	3.32%	.72	.89
8-items (3, 14, and 22 removed)	2	$X^2 = 31.76$, $p = .01$	.06 (1.02)	.23 (0.86)	0.95%	.64	.84
Distress and Coping Ability							
11-items	3	$X^2 = 24.78$, $p = .31$	.05 (0.99)	.28 (1.24)	2.84%	.73	.87
8-items (10, 16, and 21 removed)	4	$X^2 = 20.48$, $p = .20$	.04 (0.95)	.27 (1.07)	1.90%	.65	.82
Total							
16-items	5	$X^2 = 11.55$, $p = .02$	-0.10 (.13)	-0.39 (.71)	0.97%	.79	.89

Results

RELIABILITY

- The DS-II demonstrated internal consistency
  - **Meaning and Purpose: α = 0.84**
  - **Distress and Coping Ability: α = 0.82**
  - **Total: α = 0.89**
- The DS-II demonstrated test-retest reliability when symptoms stable
  - **Meaning and Purpose: ICC = .68**
  - **Distress and Coping Ability: ICC = .82**
  - **Total: ICC = .80**

Results

- **The DS-II demonstrated convergent validity** with measures of psychological distress, quality of life, and attitudes toward end-of-life.

Scale	Content	N	Min	Max	Mean	SD	DS-II Meaning & Purpose	DS-II Coping & Personal Sensitivity	DS-II Total
MSAS	Psychological	192	0	3.67	0.95	0.8	.49**	.65**	.64**
MQOL	QoL	180	0	10	7.59	2.47	-.40**	-.34**	-.41**
	Existential Wellbeing	181	0.33	10	7.45	2	-.57**	-.45**	-.57**
PHQ-9	MDE	183	0	1			.37**	.41**	.41**
SAHD	Desire to die	162	0	15	4.02	3.7	.43**	.23*	.39**
WTL	Will to live	120	0	10	8.28	2.29	-.49**	-.25*	-.44**

Results

- Discriminant validity was demonstrated, as:
  - the DS-II differentiated patients with **different functional performance levels** (Karnofsky) and **high/low symptoms** (MSAS), with a difference of 2 points on the DS-II between groups considered clinically meaningful
  - co-morbidity with depression was not found to be statistically significant at moderate levels of demoralization.

Results – Descriptive Statistics for DS-II

	Meaning and Purpose	Distress and Coping Ability	Total
Mean (SD)	3.75 (3.67)	3.89 (3.45)	7.64 (6.43)
Median (IQ range)	3 (1, 6)	3 (1, 6)	6 (3, 11)
Observed range	0-15	0-16	0-31
Possible range	0-16	0-16	0-32
Skewness	1.02	1.06	1.03
Kurtosis	0.32	0.77	0.70

Spearman's correlation coefficient between *Meaning and Purpose* and *Distress and Coping Ability* was $\rho = .61$, $p < .001$.

Clinical Implications

- **Overall, the DS-II is a 16-item, two-component scale that has demonstrated appropriate internal and external validity**
- The DS-II:
  - Reduced number of items, along with the simplified response option format = **lessen response burden**
  - **Useful clinical and research tool in meaning-centred therapies** and when patient populations are at risk of demoralization
    - e.g. advanced and serious medical disease, alcohol and substance dependence, chronic mental illness and low socio-economic groups

Demoralization Scale - II

		Never	Sometimes	Often
1	There is little value in what I can offer others.	0	1	2
2	My life seems to be pointless.	0	1	2
3	My role in life has been lost.	0	1	2
4	I no longer feel emotionally in control.	0	1	2
5	No one can help me.	0	1	2
6	I feel that I cannot help myself.	0	1	2
7	I feel hopeless.	0	1	2
8	I feel irritable.	0	1	2
9	I do not cope well with life.	0	1	2
10	I have a lot of regret about my life.	0	1	2
11	I tend to feel hurt easily.	0	1	2
12	I feel distressed about what is happening to me.	0	1	2
13	I am not a worthwhile person.	0	1	2
14	I would rather not be alive.	0	1	2
15	I feel quite isolated or alone.	0	1	2
16	I feel trapped by what is happening to me.	0	1	2

Fitting demoralization into DSM and ICD diagnostic systems

Role of 'specifiers'

Specifiers delineate phenomenological variants of a disorder indicative of specific subgroupings, which impact, among other outcomes, on treatment selection.(Regier et al, 2013)

Prototype diagnoses

In the use of dimensional prototype diagnosis, a paragraph length description of a patient's phenomenology is used by the clinician to recognize a coherent pattern among symptom variables. (DeFife et al, 2013)

Utility of demoralization as a DSM 'specifier'

- Adjustment disorder with demoralization
- Major depression with demoralization

- Use of 6 clinical vignettes across range of disciplines
- Have clinicians rate the usefulness of diagnosis to treatment decisions.

- ANZSPM
- C-L RANZCP
- COSA
- ONS
- ONSWA

- Convenience sample 320 responders

Funding: Monash Partners Aust Health Science Centre

Frequency of selection of correct diagnosis
[NB – diagnostic criteria provided]

Discipline (n=284)	Vignette 1 Normal grief (n = 281)	Vignette 2 Adjustment disorder with anxiety (n = 224)	Vignette 3 Adjustment disorder with demoralization (n = 213)
Psychiatrist - 46	96%	49% **	86% ***
Psychologist -27	93%	50% *	79% *
Social Worker – 58	93%	15% ***	67% **
Physician - 62	97%	39% ***	79% ***
Nurse - 84	92%	26% ***	78% ***
Overall -284	94%	33% ***	78% ***

* p < 0.05; ** p < 0.01; *** p < 0.001

Diagnostic utility to help understanding, selection of treatment & communication about continued care

Perceived Usefulness (VAS 0-10)	Vignette 1 Normal grief		Vignette 2 Adjustment disorder with anxiety		Vignette 3 Adjustment disorder with demoraliz<u>n</u>	
	N	M(SD)	N	M(SD)	N	M(SD)
Understanding	280	7.2(2.3)	226	7.2(2.0)	216	7.7(1.8)*
Treatment choice	280	7.3(2.3)	226	7.3(1.9)	216	7.6(1.8)*
Communication re continued care	280	7.2(2.5)	226	7.4(1.9)	216	7.7(1.7)*

* P < 0.05

Frequency of selection of correct diagnosis
[NB – diagnostic criteria provided]

Discipline (n=284)	Vignette 4 Major Depressive Disorder (n = 194)	Vignette 5 Major Depressive Disorder with Melancholia (n = 191)	Vignette 6 Major Depressive Disorder with Demoralisation (n = 186)
Psychiatrist - 46	86%	94%	79%
Psychologist- 27	83%	83%	83%
Social Worker - 58	42% ***	84%	86% ***
Physician - 62	65%	80%	77%
Nurse - 84	56% ***	80%	90% **
Overall - 284	64% ***	84%	83% ***

* p < 0.05; ** p < 0.01; *** p < 0.001

Diagnostic utility to help understanding, selection of treatment & communication about continued care

Perceived Usefulness (VAS 0-10)	Vignette 4 Major Depressive Disorder		Vignette 5 Major Depression c Melancholia		Vignette 6 Major Depression c demoralizn	
	N	M(SD)	N	M(SD)	N	M(SD)
Understanding	197	7.7(1.8)	193	7.2(1.8)	188	7.8(1.7)
Treatment choice	197	7.7(1.7)	193	7.7(1.7)	188	7.8(1.7)
Communication re continued care	197	7.7(1.7)	193	7.9(1.6)	188	7.8(1.7)

MANAGEMENT OF DEMORALIZATION

Differs from standard treatment of depression

Treatment options for Demoralization Syndrome

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

NARRATIVE REVIEW OF LIFE STORY

- Developmental history
- Eric Cassell: 'an unique life lived is a work of art'

- Raimond Gaita: 'value each person as inherently precious because of our common humanity'

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

CHANGE - Role transition

- 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

Restoring hope & meaning

- Dufault & Martocchio 1985: generalised hope rescues us when particular hopes seem lost.
- Hypothetical timelines?

6/12, 1 yr, 2 yrs

- Set goals - activity scheduling
- What tasks remain?
- Can you benefit others despite being sick?

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'.

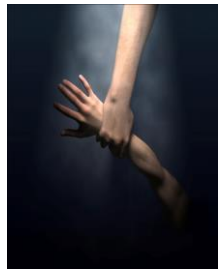
Breitbart's Meaning-centered Groups based on Frankl's logotherapy

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.

Meaning and Purpose (MaP) therapy

Lethborg et al, 2012

- **Brief individual narrative therapy (6 sessions)**
- **Uses developmental life story**
- **Seeks to portray & affirm the meaning of the life lived**
- **Identifies the continuing purpose of life despite illness & infirmity**



Dignity therapy

Chochinov et al, 2005

- **Life story**
- **When most alive?**
- **Family to remember?**
- **Key roles?**
- **What accomplished?**
- **Hopes for family?**
- **What do you want to pass on?**
- **Guidance to others?**
- **Comfort to others?**

***Chochinov et al, Lancet Oncol* 2011; 12: 753–762**

Demoralization, in conclusion

- Common
- Prevalence 15%
- Utility of adjustment disorder with demoralization
- Can measure DS-II
- Know how to ameliorate demoralization

Bramley: The hopeless dawn - Tate