Review Article

A Systematic Review of the Demoralization Syndrome in Individuals With Progressive Disease and Cancer: A Decade of Research

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Abstract

Context. Demoralization can be understood as a condition that results from existential conflict. It presents with symptoms of hopelessness and helplessness caused by a loss of purpose and meaning in life. It is a significant mental health concern given there can be an associated desire for hastened death.

Objectives. The aim of this systematic review was to synthesize the recent empirical evidence on demoralization in patients with progressive disease or cancer, including prevalence rates; the relationships between demoralization and sociodemographic, disease- and treatment-related, and psychological factors; and the psychometric properties of demoralization measures.

Methods. A comprehensive literature search using key words and subject headings was performed following PRISMA guidelines with nine electronic bibliographic databases, resulting in 25 studies (33 articles) with a total of 4545 participants reviewed. Full articles underwent methodological quality assessment, and correlational information was synthesized according to the strength of evidence.

Results. The findings suggest that demoralization is prevalent in patients with progressive disease or cancer and clinically significant in 13%–18%. A range of factors were consistently associated with demoralization: poorly controlled physical symptoms, inadequately treated depression and anxiety, reduced social functioning, unemployment, and single status. The Demoralization Scale has demonstrated good psychometric properties across five studies.

Conclusion. Overall, this systematic review was limited by the extent of variability in the characteristics of studies. Patients who are single, isolated or jobless, have poorly controlled physical symptoms, or have inadequately treated anxiety and depressive disorders are at increased risk for demoralization. Clinical recognition of demoralization can trigger more focused interventions. J Pain Symptom Manage 2015;49:595–610.

Key Words

Cancer, death, demoralization, palliative, progressive disease, psycho-oncology, terminal

Introduction

Demoralization is a common presentation of existential distress in patients at the end of life.[1] Central to its conceptualization are symptoms of hopelessness and helplessness caused by a loss of purpose and meaning in life.[1] The loss of morale spans a spectrum of mental states, from a mild loss of confidence—"disheartenment," to the beginning of losing hope and purpose—"despondency," to a state in which all hope is lost—"despair," through to severe

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demoralization where meaning and purpose are lost.[2] As demoralization has been associated with a desire for hastened death, it is thus a significant mental health concern.[2]

Demoralization has consequently emerged as a key concept in the medical psychiatric literature over the past two decades as a need for a strong conceptual understanding of the condition has been sought.[1,3,4] Because demoralization is a treatable condition, its diagnosis as a clinical syndrome will empower a better focus on potential therapeutic interventions.[1] Central to this recognition is the notion that demoralization can be differentiated from depression,[1] which is relevant as a number of medically ill patients will not develop a clinical depression, yet develop a desire to die based on suicidal thinking.[1,3] In brief, demoralization can be contrasted with depression in that the core symptoms of depression include a loss of pleasure and interest in the present moment, whereas the core symptoms of demoralization are a loss of hope and meaning, with a loss of anticipatory pleasure rather than general anhedonia.[1,3]

Currently, there are two dominant measures of demoralization: the categorically oriented Diagnostic Criteria for Psychosomatic Research (DCPR)[5] and the dimensionally directed Demoralization Scale (DS).[6] The DCPR is a structured interview, whereas the DS is a self-report questionnaire. Using the DCPR system, a diagnosis of demoralization is made if a patient has reported, for one month or more, a sense of not coping, feelings of hopelessness/helplessness, and failing to meet their own or others' expectations of them. These feelings occurred before a medical disorder developed or otherwise exacerbated it.[5] The authors of the DS proposed that demoralization presented when feelings of hopelessness and meaninglessness occurred, with an attitude of helplessness, poor coping, and a feeling of failure.[6] Although similar in conceptualization, the DCPR maintains the traditional psychosomatic integration of psyche with soma, specifically—helplessness, hopelessness, and the tendency to give up preceded the development or exacerbation of the medical illness.[5] This understanding is based on the psychosomatic notion that the mind can cause or contribute to physical illness. In contrast, the DS is empirical in nature and lacks any psychosomatic hypothesis.

In addition to these measures, the recently developed Subjective Incompetence Scale (SIS) has the potential to be another useful tool for further refinement of demoralization.[7] In the 1980s, subjective incompetence was defined as a state experienced by individuals perceiving themselves as incapable of appropriate action in demanding circumstances, much akin to hopelessness and helplessness.[8]

Although there have been several observational studies of demoralization, there has yet to be a systematic review. The aim of the present review was to synthesize the recent empirical evidence of demoralization in patients with progressive disease or cancer. Specifically, the objective of this article was to review the prevalence of demoralization; the relationships between demoralization and sociodemographic, disease- and treatment-related, and psychological factors; and the psychometric properties of instruments used to measure demoralization.

Methods

The review was guided by Preferred Reporting Items for Systematic Reviews and Meta-Analyses (The PRISMA Statement).[9] Nine electronic bibliographic databases were searched (PsycINFO, PubMed, Ovid Medline, CINAHL, Embase, Scopus, Cochrane, Informit, and Web of Science) to identify studies. The search in each database was conducted on August 16, 2013. The following search terms were used (in combination with a range of subject headings specific to each database): (cancer OR psycho-oncology OR palliative OR life limiting illness OR critical illness OR terminal* OR death OR dying OR end of life OR progressive disease OR hospice* OR life threatening illness) AND (demorali*) OR (meaning*) AND (hopeless* OR helpless* OR pointless* OR purposeless* OR giving up given up).

The inclusion criteria were 1) empirical articles or conference abstracts reporting cross-sectional or baseline longitudinal quantitative data related to the measurement of demoralization in palliative care, progressive disease, and/or cancer patient populations and 2) studies published between 2000 and 2013 to provide recent research. Stage of cancer diagnosis was not a specific inclusion criterion, as the existential threat from a cancer diagnosis is considered to be omnipresent in most people. However, as not all illnesses carry this existential threat, noncancer diagnoses needed to indicate progressive or advanced disease to generate the likelihood of an existential dimension becoming part of the patient's experience. No language restrictions were imposed. Case reports, qualitative studies, and other reviews were outside the scope of this report. The primary outcome measure was demoralization or meaninglessness and hopelessness/helplessness/purposelessness/giving up-given up. Authors of non-English articles and conference abstracts were contacted (where possible) to ask for the results of data relevant to the review that were not included in the abstracts. Six authors responded and provided additional information (Clarke, Costantini, Kiss [Hadnagy], Kissane, Mehnert, and Vehling).

Two reviewers independently assessed studies against the inclusion/exclusion criteria in a standardized manner. Studies were initially screened by title and abstract, and then, the full text for eligible studies was sourced. An eligibility criteria template was completed for each article where its inclusion could not be easily determined by scanning the full text. Any conflicts in reviewers' decisions about inclusion vs. exclusion were resolved through discussion.

Details of each study were extracted and organized with Microsoft Excel spreadsheets by the first author. Multiple articles with the same data were identified and combined through this process and considered as one study (duplicate data were reported in eight articles).[10–17] For each included study, information was extracted on:

1. Study characteristics (country, main research question(s), study design, type and number of participants, age range and/or mean and SD, measure of demoralization, main finding(s), and quality rating);
2. Prevalence rates of demoralization (prevalence rate as a percentage; where prevalence was not reported for DS studies only, the mean and SD were used to calculate the threshold for the clinically meaningful presence of demoralization with M + 1 SD);
3. Relationships with sociodemographic, disease- and treatment-related, and psychological factors (correlations, *b* values, and analysis of variance results);
4. Psychometric properties of demoralization measures (factor structure, reliability [internal consistency and test-retest reliability], and construct validity [convergent validity and divergent validity]).

Methodological quality appraisal was completed with the Standard Quality Assessment Criteria for Evaluating Primary Research Papers,[18] which has been an effective tool for quality appraisal of observational studies.[18] It has 11 criteria to assess quality. For each criterion, a score of 2 was given for fully meeting the criterion, 1 for partially meeting the criterion, and 0 for not meeting the criterion. A summary score was calculated with this score indicative of methodological quality.[18] Although systematic reviews of quality appraisal for observational studies have reported that the checklists and tools can vary widely,[19,20] nonetheless this method has been used in recent years in a similar population[21] and has been cited by more than 80 articles in Google Scholar. The first author completed the methodological quality appraisal (Table 1).

Overall assessment of correlational information was organized into four evidence levels. This categorization was drawn from a recent systematic review with cancer patients.[21] Accordingly, 1) consistent findings of significant group differences or a relationship in the same direction (or no relationship) in at least three studies = strong evidence; 2) significant group differences or a significant relationship in the same direction in two studies with none or only one in the opposite direction = moderate evidence; 3) no clear directionality or group differences were evident = inconsistent evidence; and 4) only one study available with supporting evidence = weak evidence.

Results

The search strategy identified 1057 citations. After removal of duplicates, 360 studies remained. These were screened by title and abstract, and 293 studies were excluded as they did not meet the eligibility criteria. The full texts for the remaining 67 studies were assessed for eligibility, with a total of 25 studies (33 articles) included in the systematic review. The main reasons for exclusion included: the article did not report quantitative data, the construct of demoralization or similar (meaninglessness and hopelessness, helplessness, pointlessness, or giving up-given up syndrome) was not examined, and the study population was not receiving palliative care or did not have a progressive disease or cancer. Eight articles reported duplicate study data. Figure 1 depicts a flow diagram of included studies.

The majority of the studies (n = 22, 88%) were cross-sectional, all but two studies (92%) were published in English, and five (20%) were abstracts only. Sample sizes for the included studies varied from a minimum of 19 participants to a maximum of 750, with 4545 participants across all studies. The inclusion criteria were adults aged 18 years and over who were receiving palliative care (two studies, 8%), had a progressive disease (two studies, 8%), or had an active diagnosis of cancer, any stage and type (18 studies, 72%). In three studies (12%), patients had different types of medical diseases, among them progressive diseases or cancer. Demoralization was measured with the DS in 13 studies (52%), the DCPR in five studies (20%), the SIS in two studies (8%), or by measuring a combination of loss of meaning/meaninglessness and hopelessness, helplessness, or purposelessness in five studies (20%).

The DS is a 24-item Likert scale (score range 0–96).[6] It has five subscales: loss of meaning and purpose, dysphoria, disheartenment, helplessness, and sense of failure.[6] The DCPR is a structured interview for the diagnosis of psychosomatic syndromes.[5] The interview consists of 58 items scored in a yes/no response format to assess for one of 12 psychosomatic syndromes, one of which is demoralization, assessed with five items.[5] The SIS is a newly developed scale with 12 items (score range 0–36).[7] The SIS has two

Table 1
Study Characteristics

Source	Country	Main Research Question(s)	Study Design, Type, and Number of Participants	Age (Years) (Range, and/or M ± SD)	Demoralization Measure	Main Relevant Finding(s)	Quality Rating[a]
Boscaglia and Clarke (2007);[36] Clarke (2011);[10] Clarke and Boscaglia (2011)[11]	Australia	Is sense of coherence (SOC) a protective factor for demoralization?/ Benchmark level of demoralization?/ Demoralization explained by trait characteristics?	Cross-sectional, outpatients with gynecologic cancer, $n = 120$	20–70, 52.2 ± 11.9	DS	SOC likely a protective factor against demoralization/The DS is a sensitive measure/Low SOC and self-blame coping style predictive of depression and demoralization; low appraised controllability of cancer dx predictive of higher demoralization. Spirituality not significantly related to demoralization directly—relationship mediated through "meaningfulness." **Demoralization M (SD) = 22.2 (16.8)**	0.80
MJ. Clarke (2011)[40]	U.S.	The parceling of depression and demoralization?	Cross-sectional, hospitalized bone marrow transplant patients, $n = 50$	NR, 53.6 ± 12.2	DS	The DS was highly correlated with the MMPI-2 demoralization scale. The DS significantly predicted depression measured with the HADS	NR
Clarke, McLeod, Smith, Trauer, and Kissane (2005)[38]	Australia	Psychosocial and physical functioning comparison for MND vs. metastatic cancer?	Cross-sectional, motor neurone disease (MND) and metastatic cancer, $n = 251$ (126 = MND; 125 = cancer)	NR, 62.9 ± 11.5 (MND), 67.6 ± 12.1 (cancer)	Monash Interview for Liaison Psychiatry	MND patients: higher demoralization, hopelessness, and suicidal ideation than cancer patients. Cancer patients: higher anhedonia than MND patients. **MND demoralization M (SD) = 24.3 (21.4–27.2 CI). Cancer demoralization M (SD) = 16.9 (14.9–19.0 CI)**	0.85
Cockram, Doros, and De Figueiredo (2009)[7]	U.S.	Psychometric properties of the SIS?	Cross-sectional, colorectal or gastrointestinal cancer outpatients, $n = 112$	20–81, 52.5 ± 12.2	SIS	SIS demonstrated adequate reliability and validity. **Basic SI M (SD) = 7.2 (3.7). Severity SI M (SD) = 15.8 (9.6).**	0.70

Cockram, Doros, and De Figueiredo (2010)[45]	U.S.	At different levels of perceived stress and social support, what is the relationship between depression and subjective incompetence (SI)?	Cross-sectional, colorectal or gastrointestinal cancer outpatients, $n = 71$	28–85, 61.9 ± 13.5	SIS	When social support was low and perceived stress high OR when both high or low, depression and SI were positively correlated; when perceived stress was low and social support high, depression and SI were negatively correlated	0.80
Costantini et al. (2013)[39]	Italy	Psychometric properties of the Italian DS?	Cross-sectional, advanced cancer, $n = 100$	NR, 55.6 ± 11.6	DS	DS demonstrated reliability and validity. Ontologic differences found between depression and demoralization. **Demoralization M (SD) = 23.9 (14.5)**	NR
Fang, Chiu, Yeh, Pi, and Li (2012)[42]	Taiwan	Association between depression, demoralization, and post-traumatic growth?	Cross-sectional, cancer at different stages, $n = 86$	NR, NR	DS-MV	Distress correlated positively with demoralization; DS loss of meaning was negatively related to PTGI new possibilities and PTGI personal strength; DS sense of failure was negatively related to PTGI relating to others, PTGI new possibilities, and PTGI personal strength. **Demoralization M (SD) = 28.8 (12.6)**	NR
Grandi, Sirri, Tossani, and Fava (2011)[24]	Italy	Psychological features of demoralization and its similarities to MDD?	Cross-sectional, heart transplant patients, $n = 95$	NR, 55.6 ± 10.1	DCPR	Demoralization related to impairments in physical, psychological, social, and environmental QOL and in psychological well-being, particularly self-acceptance and environmental mastery. Demoralization positively related to distress and higher in women and single patients. Comorbid depression did not affect this pattern. **Demoralization prevalence = 32.6%**	0.80

(*Continued*)

Table 1
Continued

Source	Country	Main Research Question(s)	Study Design, Type, and Number of Participants	Age (Years) (Range, and/or M ± SD)	Demoralization Measure	Main Relevant Finding(s)	Quality Rating[a]
Grassi, Rossi, Sabato, Cruciani, and Zambelli (2004);[25] Grassi, Sabato, Rossi, Biancosino, and Marmai (2005)[12]	Italy	Applicability of DCPR and relationship with other measures?/DSM-IV and DCPR comparison?	Cross-sectional, outpatients with a diagnosis in the past 18 months, $n = 146/105$	27–70, 57.4 ± 10.3/55.5 ± 10.4	DCPR	Demoralization: one of three DCPR conditions most prevalent and related to increased hopelessness. **Demoralization prevalence = 28.8%**	0.85/0.80
Hadnagy, Csikos, and Nagy (2012)[37]	Hungary	Depression and demoralization comparison?	Cross-sectional, institutional, and home hospice patients, $n = 19$	NR, NR	DS	Demoralization occurred at a higher rate than depression. The rate of patients with severe demoralization but no clinical depression was 10.5%–21%. **Demoralization M (SD) = 61.3 (12.4)**	NR
Hung et al. (2010);[13] Lee et al. (2012)[31]	Taiwan	Psychometric properties of the Mandarin DS?/Characteristics of demoralization and relationship with psychosocial factors?	Cross-sectional, cancer at different stages, $n = 214/234$	NR, NR	DS-Mandarin	DS-Mandarin demonstrated reliability and construct validity/Occupation, cancer diagnosis, and treatment had a significant effect on demoralization. **Demoralization M (SD) = 31.1 (14.9)**	NR/0.90
Jacobsen et al. (2006)[41]	U.S.	Are cluster symptoms that measure demoralization separate from cluster symptoms measuring depression?	Cross-sectional, advanced cancer, $n = 242$	NR, 57.1 ± NR	Sections from the SCID, McGill QOL, Brief COPE, CGA, YES, and GSES	Separate demoralization and depression factors were found. Demoralization characterized by seven symptoms (loss control, loss hope, anger/bitterness, sense failure, feeling life burden, loss meaning, and belief life's meaning dependent on health). Demoralization was associated with patient's inner peacefulness. **Demoralization prevalence = 11.4%**	0.85

Katz, Flasher, Cacciapaglia, and Nelson (2001)[29]	U.S.	Factor structure of the Mohr Psychosocial Questionnaire?	Cross-sectional, cancer and lupus, $n = 87$ (56 = cancer; 31 = lupus)	NR, 53 ± NR	Mohr's Psychosocial Questionnaire—demoralization factor	Demoralization was positively correlated with total mood disturbance and average pain ratings and inversely related to benefit finding.	0.80
Kissane et al. (2012)[43]	U.S.	Psychometric properties of the Shame and Stigma Scale?	Longitudinal, head and neck cancer, $n = 104$	Median (interquartile range) = 57 (47–67)	DS	SSS correlates with DS ($r = 0.60$)	0.80
Kissane et al. (2004)[6]	Australia	Psychometric properties of the DS?	Cross-sectional, advanced cancer, $n = 100$	NR, 59.3 ± 12.2	DS	Five factors found—showed high internal reliability and convergent validity with similar scales. Divergent validity found. **Demoralization M (SD) = 30.8 (17.7)**	0.90
Mangelli et al. (2005);[26] Rafanelli et al. (2013);[15] Sirri et al. (2012)[16]	Italy	Rates of demoralization and depression?/ Characterization of demoralization?/ Prevalence of Type A behavior?	Cross-sectional, medical outpatients (of relevance: heart disease and cancer), $n = 351$ heart disease; 104 cancer	NR, NR	DCPR	Less demoralization, depression, and worry in cardiac patients with Type A behavior compared with other groups. **Demoralization prevalence = 32.3% heart transplantation; 33.3% myocardial infarction; and 32.7% cancer**	0.75/0.85/ 0.95
Mehnert, Vehling, Hocker, Lehmann, and Koch (2011a/2011b)[14,30]	Germany	Psychometric properties of German DS?/ Prevalence of demoralization?	Cross-sectional, advanced cancer, $n = 516$	18–88, 57.9 ± 11.9	DS	DS demonstrated validity and reliability with high clinical relevance in advanced cancer/ Demoralization frequent syndrome and distinct from depression. **Demoralization M (SD) = 29.8 (10.4)**	0.90
Morita, Tsunoda, Inoue, and Chihara (2000)[32]	Japan	Factor structure of scale designed measure existential distress?	Cross-sectional, hospice inpatients, $n = 162$	NR, 63 ± 12	Study-specific measure of existential distress	Factor analysis yielded two factors: meaningless and hopelessness, which together capture demoralization. **Demoralization prevalence = 37% (meaninglessness); 37% (hopelessness)**	0.80
Mullane, Dooley, Tiernan, and Bates (2009)[22]	Ireland	Psychometric properties of DS?	Cross-sectional, inpatients with advanced palliative cancer, $n = 100$	NR, 64.3 ± 11.6	DS	DS demonstrated reliability and convergent validity. Demoralization not separate from depression. **Demoralization M (SD) = 19.9 (14.6)**	0.75

(*Continued*)

Table 1
Continued

Source	Country	Main Research Question(s)	Study Design, Type, and Number of Participants	Age (Years) (Range, and/or M ± SD)	Demoralization Measure	Main Relevant Finding(s)	Quality Rating[a]
Nanni, Travado, Palma, Silvestrini, and Grassi (2011)[27]	Portugal and Italy	Depression demoralization comparison between Southern European countries?	Cross-sectional, cancer outpatients, $n = 195$	18–70, 53.4 ± 10.3	DCPR	No differences between populations found. **Demoralization prevalence = 24.0%**	NR
Passik, Inman, Kirsh, Theobald, and Dickerson (2003)[34]	U.S.	Psychometric properties of scale measuring boredom (purposelessness, understimulation, boredom)?	Cross-sectional, cancer, $n = 100$	NR, 62.4 ± 13.4	PUB—boredom related to spirituality and meaning factor	The PUB yielded two factors: the factor "boredom related to spirituality and loss of meaning" was akin to demoralization.	0.80
Rafanelli, Milaneschi, and Roncuzzi (2009)[28]	Italy	Level of distress, psychological well-being, and clinical and subclinical depression?	Longitudinal, congestive heart failure, $n = 68$	43–93, 75.4 ± 10.9	DCPR	High prevalence of somatic complaints, depression, and demoralization. Psychological well-being low. **Demoralization prevalence = 20.6%**	0.80
Sautier, Vehling, and Mehnert (2014)[44]	Germany	Psychometric properties of German Patient Dignity Inventory-German (PDI-G)?	Cross-sectional, inpatients with cancer, $n = 112$	19–75, 56.3 ± 13.9	DS	Concurrent validity was found with the DS ($r = 0.67$)	0.85
Vehling et al. (2011, 2012)[35,17]	Germany	Role of meaning and meaning-related life attitudes predict psychological and existential distress?/ Global meaning and demoralization predicted by cancer stage, palliative treatment, and physical problems?	Longitudinal, cancer, $n = 270$	18–88, 56.9 ± 13.9	DS	Global sense of meaning protective factor against distress symptoms. Risk of existential distress across all disease stages. Physical problems predict who becomes demoralized. **Demoralization M (SD) = 22.2 (13.9)**	0.85/0.90
Vehling, Oechsle, Koch, and Mehnert (2013)[33]	Germany	Occurrence and predictors of demoralization?	Cross-sectional, cancer, $n = 750$	18–75, 57.7 ± 12.2	DS	Demoralization related to complex interaction of demographic and medical characteristics. **Demoralization M (SD) = 20.8 (13.9)**	0.95

SOC = sense of coherence; NR = not reported; DS = Demoralization Scale; HADS = Hospital Anxiety and Depression Scale; dx = diagnosis; SIS = Subjective Incompetence Scale; PTGI = Post-Traumatic Growth Inventory; MDD = major depressive disorder; DCPR = Diagnostic Criteria for Psychosomatic Research; QOL = quality of life; SCID = Structured Clinical Interview for the DSM-IV; CGA = Complicated Grief Assessment; YES = Yale Evaluation of Suicidality; GSES = General Self-Efficacy Scale; PUB = Powerlessness, Understimulation, Boredom Scale; SSS = Shame and Stigma Scale.
[a]Quality rating is an approximate only.

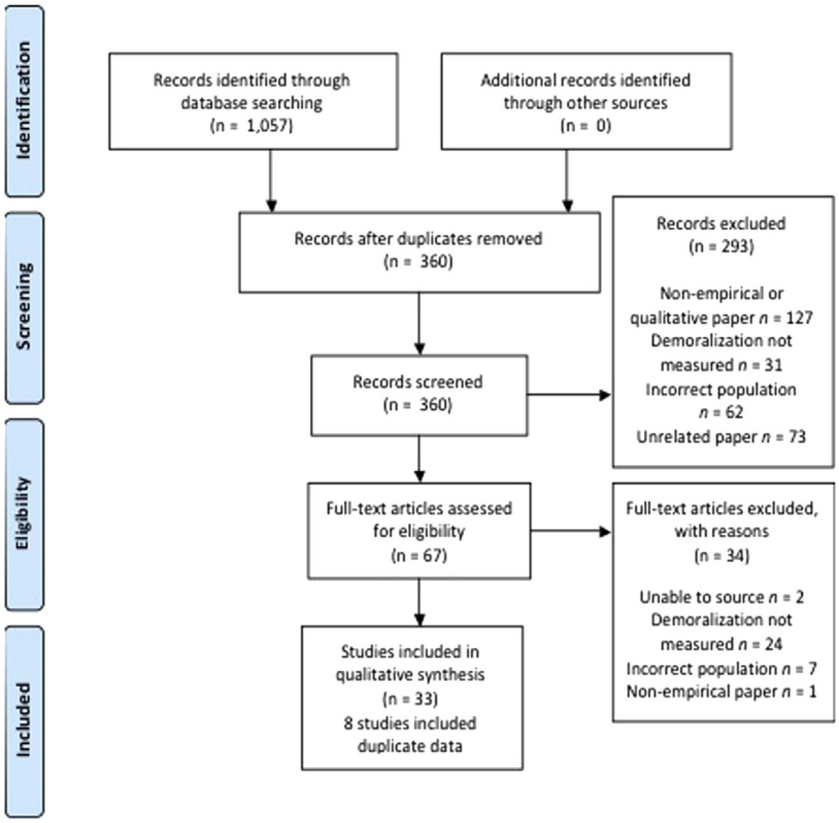

Fig. 1. Flow diagram of included studies.

factors: the Basic SI score (number of items scored other than 0; range 0–12) and the Severity SI score (sum of the weighted scores; range 0–36).

Of the 13 studies that used the DS, mean scores and SDs for the total DS score were reported in 10 studies. The authors of these studies were e-mailed with a request for the number of participants who scored above the demoralization total mean score plus one SD. It was calculated for seven of these studies. This has been suggested to be the most statistically sound method of determining the cutoff score for potential caseness (i.e., threshold for the clinically meaningful presence of demoralization).[22] Prevalence rates of demoralization were reported in the five DCPR studies. The remaining 10 studies were excluded from this aim. Relationships with other factors were reported in all 25 studies, whereas the psychometric properties of demoralization measures were reported in six studies (five studies = DS; one study = SIS). Five studies were unable to be quality appraised because the findings were reported in abstracts only. Table 1 summarizes study characteristics.

Given there were marked variations in the type of participants and the type of demoralization measures used, thus significant heterogeneity, the focus was on qualitative synthesis rather than meta-analysis.[9,23] This synthesis involved describing the characteristics of each study and the results of each study that were applicable to the aims of the review.

Prevalence of Demoralization

In the five studies ($n = 959$ subjects) in which the DCPR was used, prevalence of demoralization ranged from 20.6% to 33.3%,[24–28] as shown in Table 1. The prevalence of demoralization in 10 studies ($n = 2295$ subjects) using the DS is reported in Table 2, in which clinically significant demoralization was found in 13%–18% of participants.

Clinical Presentation of Demoralization Syndrome

Sociodemographic Factors. There were similar findings for the relationship between marital status and demoralization with the results of three studies ($n = 723$) indicating that having a partner was associated with lower levels of demoralization. Specifically, demoralization was more frequent in single patients in the study by Grandi et al.,[24] and married participants were less demoralized than divorced or separated participants in the study by Katz et al.[29] Mehnert et al.[30] reported higher levels of demoralization among participants living alone compared with those living with a partner. However, as an outlier, in the study by Lee et al.[31] ($n = 234$), no differences were found in the level of demoralization by marital status. There

Table 2
Threshold for the Clinical Presence of Demoralization With the DS

Source	M (SD)	M + 1 SD	Prevalence Clinically Significant (%)
Boscaglia and Clarke (2007)[36]/ Clarke (2011)[10]/ Clarke and Boscaglia (2011)[11]	22.2 (16.8)	38.9	18
Costantini et al. (2013)[39]	23.9 (14.5)	38.4	14
Fang et al. (2012)[42]	28.8 (12.6)	41.4	NR
Hadnagy et al. (2012)[37]	61.3 (12.4)	73.7	NR
Hung et al. (2010)[13]/ Lee et al. (2012)[31]	31.1 (14.9)	45.9	NR
Kissane et al. (2004)[6]	30.8 (17.7)	48.6	18
Mehnert et al. (2011a/2011b)[14,30]	29.8 (10.4)	40.2	16
Mullane et al. (2009)[22]	19.9 (14.6)	34.6	13
Vehling et al. (2011/2012)[35,17]	22.2 (13.9)	36.1	15.5
Vehling et al. (2013)[33]	20.8 (13.9)	34.7	15.7

DS = Demoralization Scale; M (SD) = mean and standard deviation; NR = not reported or information not obtained from authors.

was also consistent evidence for a relationship across four studies ($n = 1153$ subjects) between a higher level of demoralization and reduced social support and social functioning.[24,25,32,33]

There was evidence for a relationship between employment and demoralization (two studies, $n = 321$ subjects), with employed patients or patients with full-time jobs reported as less demoralized than jobless patients.[29,31] Mostly consistent evidence was reported for spirituality (two studies, $n = 616$ subjects). Spiritual problems were associated with higher demoralization,[30] and spirituality and religious beliefs were negatively related to demoralization.[34] However, in the study by Clarke and Boscaglia,[11] spirituality was not directly related to demoralization, but this relationship was mediated by meaningfulness.

Mixed findings were reported for age, gender, and education. For example, no consistent association between age and demoralization was found. In the study by Katz et al.,[29] demoralization was unrelated to age, yet in the study by Vehling et al.[35] in 2011, older age was associated with higher levels of demoralization. In contrast, a negative correlation between age and demoralization was reported in two studies totaling 1266 subjects.[30,33] This may be explained by the results of the study by Vehling et al. in 2013,[33] in which the effect of curative vs. palliative treatment moderated the relationship between demoralization and both age and gender. Specifically, the relationship between age and demoralization was negative for women receiving palliative treatment and positive for men receiving palliative treatment. In four studies ($n = 1631$), demoralization was higher or more frequent in women.[24,30,33,35] However, in two studies ($n = 339$), no differences in gender were found.[12,31] Likewise, no clear relationship between education and demoralization has been established. In one study, patients with only a high school education were more demoralized than those with some level of college/tertiary training,[29] whereas in another study, no differences were found.[31] There was little research regarding income and religion. One study reported that demoralization was higher in low-income earners than those with high incomes, and there were no differences in demoralization across religions.[31]

Disease- and Treatment-Related Factors. Uniformly, the findings suggest that there is no association between demoralization and time since diagnosis (three studies, $n = 723$),[29,30,36] stage of disease (four studies, $n = 770$),[17,25,31,36] and type of treatment (three studies, $n = 650$).[17,25,31] There is consistent evidence to suggest that demoralization is associated with physical problems (six studies, $n = 1788$),[25,29,30,33,35,37] particularly fatigue, mobility constraints, breathing problems, constipation, and memory or concentration problems.[35] Furthermore, evidence suggests that there is a negative association between activity level and demoralization (two studies, $n = 233$).[25,29]

There were inconsistent findings regarding the association between cancer site and demoralization, with head and neck cancer more frequently associated with demoralization than cervical or gastrointestinal cancer in one study.[31] Yet, in another large study involving patients with heterogeneous cancers, no association was found.[30]

There was little research regarding the effect of illness type on demoralization. Motor neuron disease patients reported higher demoralization than metastatic cancer patients in one study.[38] In another study, lupus patients were more demoralized than cancer patients.[29]

Psychological Factors. There were consistent findings for a strong positive relationship between demoralization and depression (11 studies, $n = 2372$),[6,17,22,25,29–31,33,37,39,40] anxiety (four studies, $n = 968$),[24,29,30,35] and a desire for hastened death (three studies, $n = 442$).[6,22,41] Uniformly, the evidence indicated a strong negative relationship between demoralization and quality of life (five studies, $n = 675$).[6,22,24,25,31] Demoralization has been positively related to distress (two studies, $n = 602$)[30,42] and negatively associated with hopefulness (two studies, $n = 200$)[6,22] and with purpose in life (two studies, $n = 611$).[24,30]

There was insufficient research to examine an association between demoralization and a range of coping factors or coping responses. The relationship with such constructs has only been examined in single studies thus far. In this research, there was a positive relationship between demoralization and use of self-blame to cope with cancer and low appraised

controllability of the cancer diagnosis;[11] denial, behavioral disengagement, and self-blame;[7] somatization and hostility;[24] cancer-related concerns;[25] inability to accept the cancer diagnosis;[41] anger and confusion;[29] shame and stigma;[43] emotional problems;[30] dependency and burden on others;[32] and dignity-related distress.[44] There was a negative relationship between demoralization and sense of coherence;[36] autonomy, environmental mastery, and self-acceptance;[24] adjustment;[25] inner peacefulness;[41] Type A behavior;[16] and global meaning and goal seeking.[35] No association was found between demoralization and post-traumatic growth.[42] More complex relationships were reported in the study by Cockram et al.,[45] who found that when perceived stress was low and social support was high, the correlation between depression and subjective incompetence (demoralization) was strong and negative. However, when perceived stress and social support were either both high or both low, the relationship between subjective incompetence and depression was positive and moderate. Alternatively, when there was high perceived stress and low social support, the relationship was positive but not of statistical significance.

Psychometric Properties of Demoralization Measures

The DS has demonstrated acceptable-to-good psychometric properties across five studies as reported in Table 3. Costantini et al.[39] have highlighted that the factor structure is not conclusive and requires further analyses with larger samples. In four of the five validation studies, divergent validity was reported.[6,13,30,39] Some studies did not focus on the validation of the DS but nonetheless reported divergent validity. For example, in the study by Hadnagy et al.,[37] the rate of severe demoralization but no clinical depression was between 10.5% and 21% (determined with cutoff values from Mehnert et al.[30] and Kissane et al.,[6] respectively). Similarly, in the study by Lee et al.,[31] with a cutoff value of 30, the rate of severe demoralization but no clinical depression was 27.4%. Divergence of the construct of demoralization from depression also has been reported in studies in which the DCPR or other measures were used. For instance, using the DCPR, 71% of participants classified as demoralized were not depressed.[24] In another study, 14.8% participants who were demoralized did not have a formal *Diagnostic and Statistical Manual of Mental Disorders* (DSM)-IV diagnosis of major depressive disorder (MDD).[12] In the study by Jacobsen et al.,[41] in which these authors designed their own measure of demoralization, 14.8% of participants with syndromal demoralization (participants who scored in the top 10% on their DS) met DSM-IV criteria for MDD. Nonetheless, divergent validity has not been fully established, as high correlations between demoralization and depression were reported in all studies, demonstrating a level of convergence between the two constructs.

The psychometric properties of the SIS have been reported in one study;[7] thus, the validation of this measure is considered preliminary. In this study, the SIS yielded two factors, "Basic Subjective Incompetence" and "Severity Subjective Incompetence." In addition, the SIS demonstrated convergent validity with the Brief Cope Scale, and internal reliability for the total scale was $\alpha = 0.90$.

Discussion

This review had the broad aim of synthesizing empirical evidence on demoralization in patients with progressive disease or cancer. Twenty-five studies

Table 3
Summary of Results for the DS Validation Studies

Source	Country/ Translation	Factor Structure	Internal Reliability		Convergent Validity	Divergent Validity
			Total	Subscales		
Costantini et al. (2013)[39]	Italy	Loss of meaning and purpose, dysphoria, disheartenment, helplessness, sense of failure	0.90	0.50–0.84	BDI, MAC	6%–20% High demoralization but no clinical depression
Kissane et al. (2004)[6]	Australia	Loss of meaning and purpose, dysphoria, disheartenment, helplessness, sense of failure	0.94	0.71–0.89	McGill QOL, PHQ, BDI, BHS, HOPES, SAHD	7%–14% High demoralization but no clinical depression
Hung et al. (2010)[13]	Taiwan	NR	0.93	0.63–0.85	BHS, McGill QOL	23.4% High demoralization but no clinical depression
Mehnert et al. (2011)[30]	Germany	Loss of meaning and purpose, dysphoria, disheartenment, sense of failure	0.84	0.76–0.88	DT, PHQ, GAD-7, LAP-R	5%–20% High demoralization but no clinical depression
Mullane et al. (2009)[22]	Ireland	Loss of meaning and purpose, dysphoria, disheartenment, helplessness, sense of failure	0.93	0.72–0.86	BDI, PHQ, BHS, SAHD, McGill QOL, HOPES	2.1%–5.2% High demoralization but no clinical depression

DS = Demoralization Scale; BDI = Beck Depression Inventory; MAC = Mini-mental Adjustment to Cancer; McGill QOL = McGill Quality of Life Scale; PHQ = Patient Health Questionnaire 9 items; BHS = Beck Hopelessness Scale; HOPES = Hunter Opinion and Personal Expectations Scale; SAHD = Schedule of Attitudes Toward Hastened Death; NR = not reported; DT = Distress Thermometer; LAP-R = Life Attitude Profile-Revised.

(33 articles) were identified, and there was wide variation in the content of each.

The prevalence of demoralization was reported for five studies in which the DCPR was used and was calculated in seven studies in which the DS was used. Thus, the prevalence of demoralization varied by measure and threshold for clinical caseness. When the DCPR was used as a categorical measure, rates of demoralization ranged from 21% to 33%.[24–28] Alternatively, when the DS was used, rates of demoralization were reported dimensionally, with 13%–18% calculated as having clinically significant demoralization.[6,22,30,33,35,36,39] This latter approach appears more clinically useful, as it is likely that demoralization exists on a continuum,[22] ranging from what would be a normal response to one that was leading to impairment. The most recent edition of the DSM, the DSM-5, acknowledges the limitations of categorical diagnosis and has shifted the conceptualization of some disorders to a dimensional focus.[46] Such an approach enables the clinician greater opportunity to examine the severity of a condition and tailor treatment proportionally.[46] With a focus on acuteness of symptoms, clinicians are able to better gather information leading to increased insight when treatment planning.[46]

With regard to such a continuum, moderate levels of demoralization would be consistent with DSM-5 adjustment disorder. This disorder is a broad and loose category that is used to describe emotional or behavioral symptoms of poor coping that are a response to a stressor in the past three months.[46] It is required that the level of distress is out of proportion to the severity of the stressor (allowing for cultural differences) or with impaired social, occupational, or some other area of functioning.[46] Finally, the condition is not severe enough to meet criteria for another mental disorder such as MDD.[46] Perhaps, if moderate demoralization was diagnosed as adjustment disorder with demoralization, it may better describe the patient's experience and result in greater ownership by the patient. From clinical experience, we believe physicians also appear to make more sense of demoralization than adjustment disorder alone. Regardless, moderate levels of demoralization would likely respond well to psychotherapy.[47]

Severe demoralization may benefit from its separate syndromal diagnosis and can clearly be comorbid with clinical depression.[30] When such comorbidity is present, treatment with both antidepressants and psychotherapy appears indicated.[48] Depression within psychiatry places emphasis on mood and loss of interest or pleasure in the here and now, the anhedonic state.[46] The DSM-5 is silent about the role of meaning and purpose in life in depressive disorders,[46] yet palliative care has recognized the salience of pointlessness to the will to live.[6,22,41] Overall, the dimensional approach to the assessment of demoralization is more comprehensive and has greater potential to inform treatment.

Strong evidence emerged for a relationship between demoralization and persisting physical problems, reduced quality of life, and psychological factors such as depression, anxiety, and a desire for hastened death. Poorly controlled physical symptoms, such as pain, can quickly challenge a patient's coping and lower their morale. In a like manner, unrecognized anhedonic depression will eventually lower morale and deepen suffering. There was also strong evidence for relationships between demoralization and being without a partner and reduced social functioning, which is consistent with the evidence that social isolation negatively impacts health and well-being.[49,50] Interestingly, time since diagnosis and stage of disease (specifically in relation to cancer) were not associated with a patient's level of demoralization. This is probably the effect of the high prevalence of cancer and the well-known existential threat it imposes regardless of stage.

Moderate evidence was found for a relationship between demoralization and sociodemographic factors such as unemployment, spiritual problems, or lack of a clear spiritual dimension to a person's life and for psychological factors such as distress, hope, purpose, and sense of coherence about the value of life. Although there was inconsistent or weak evidence for an association between demoralization and sociodemographic factors such as age, gender, education, income, and religion, this might be an artifact of the heterogeneity of the cohorts and the minimal research published thus far.

Female gender may result in demoralization being more common when comorbid depression is present, as depression is recognized as more likely to occur in women for a range of reasons, in particular, because of estrogen receptors in the limbic system regulating mood.[51,52] However, for less-severe levels of demoralization, where clinical depression is not a commonly comorbid condition,[22,30,39] gender might not be predictive, as morale may fluctuate irrespective. Younger age may bring more demoralization if time has not permitted adaptation to the threat of illness. Nevertheless, life is precious to most people, including elderly persons, potentially rendering age per se not a strong predictor of morale. The study by Vehling et al.[33] provided some insight into the complex relationships that may exist among sociodemographic factors and demoralization with the interaction of age, gender, and treatment type affecting the level of demoralization. In addition, being well educated and earning a higher income may have many benefits,

but wealth neither guarantees good health nor hinders physical decline. Spirituality is closely linked with hope, purpose, and meaning,[53] which likely act as a safeguard for morale depletion in response to ill health. Overall, there are a range of factors whereby moderate, weak, or inconclusive evidence has been provided, which highlights the relatively recent research interest in demoralization and the need for further study in this area to deepen understanding of the factors associated with demoralization.

Of the studies examining psychometric properties of demoralization measures, there was consistent evidence to suggest that the DS has convergent validity and internal reliability for the total scale.[6,13,22,30,39] Thus far, there is less evidence to suggest that the SIS has adequate psychometric properties, given there was only one published validation study at the time of this review.[7] Further validation studies, therefore, are required to determine the utility of this scale. In relation to the DS, however, although steady evidence has been reported for convergence and internal reliability, there still remain inconsistencies with the factors in different cultural settings. Moreover, some of the subscales have shown weak internal reliability, and test-retest reliability has yet to be examined.

A key issue lies with the establishment of divergent validity between demoralization and depression because the empirical findings suggest consistently some level of convergence. At the same time, however, there is clear evidence that a substantial percentage of participants can present with "syndromal" demoralization, yet not be classified as clinically depressed. This evidence provides strength to the argument regarding the clinical importance of demoralization and the need for it to be considered a separate psychiatric syndrome according to formal classification standards.[3] Further fieldwork is clearly needed to strengthen the empirical evidence for the divergent boundaries of these constructs. As noted in the Introduction, this is essential given that a number of medically ill patients are not diagnosed with depression because they lack anhedonia, yet develop a desire to die because of feelings of pointlessness and meaninglessness.[1,3]

In considering how suicidal thinking develops, we conceptualize that inadequately treated physical symptoms, functional limitations, poor social support, reduced spiritual well-being, and inadequately treated psychiatric disorders (including anhedonic depression) are potential moderators of the development of a desire to die. Importantly, hopelessness, worthlessness, meaninglessness, and shame are the potential mediators of suicidal thinking.[54] Long ago, Beck et al.[55] first showed that hopelessness was an independent and more powerful predictor of suicidality than depression; today, we appreciate that the mental state of hopelessness is a mediator of suicidality.[56] Similarly, as another mediator of suicidality, meaninglessness as found in the demoralized is a crucial mental state to recognize alongside clinical depression, rather than the former being merely subsumed under the latter.[1] Future studies that differentiate moderators from mediators of the desire to die would be beneficial.

The studies included in this review had a number of limitations. For example, most involved homogeneous samples in terms of sociodemographic factors, with the majority middle to older aged, white, married, and of Christian faith. Furthermore, the recruitment methodology, whereby participation was voluntary and reliant on referral from medical practitioners, is likely to have been subject to selection bias, resulting in an underestimation of demoralization. Specifically, those experiencing demoralization may have been less likely to respond and/or participate, a well-recognized bias in recruitment of cohorts of palliative care patients. Finally, among the validation studies, use of modern psychometric validation techniques such as item response theory (IRT) models was not considered.[57] IRT models have gained a reputation in recent years as a suitable option for scale development in the health sciences.[58] These models are used to examine the performance of each item in a scale, which when combined gives a clearer picture of how the scale functions as a whole in measuring the construct of interest.[59] Such models have been used in the development of the Functional Assessment of Cancer Therapy quality of life scales[60] and have great potential for use in the validation of demoralization measures.

A limitation of this review was the inclusion of studies that used various measures of demoralization, which reduced the capacity to compare findings. The extent of variability in what each measure was capturing also needs to be considered. For example, Costantini et al.[39] found that participants who were demoralized according to the DCPR had significantly higher demoralization scores on the DS than participants who did not have DCPR demoralization. Nonetheless, Grassi et al.[25] proposed that assessment of demoralization with the DCPR cannot be compared with that of the DS because of the different criteria in each. Grassi et al. highlighted the need for more research in this area. Finally, another noteworthy shortcoming of this review is the inclusion of heterogeneous populations. A study was included if the sample was drawn from a palliative care, progressive disease, or oncology population. However, the extent to which these populations may be considered comparable could be subject to debate. Nonetheless, the broad eligibility criteria were chosen with the aim of exploring as much of the demoralization literature as possible with populations that are facing existential threat.

Perhaps, a means of moving forward would be to integrate aspects of the DCPR criteria with the criteria proposed by Kissane et al.[1] These authors selected, for consistency with DSM standards, two weeks rather than four for the length of time for which the mental state persists. Nonetheless, the arbitrary nature of such periods can be overlooked when the focus is on the clinical need for a persisting rather than a passing state of mind. A greater focus was placed on a sense of meaninglessness and purposelessness, alongside hopelessness/helplessness and given up states of mind in the definition by Kissane et al.,[1] whereas the DCPR criteria left out meaning-based constructs in its criteria. Although Kissane et al. did not enunciate unmet expectations and poor coping in their written criteria, it was acknowledged[3] and could readily be incorporated. The DCPR holds the traditional psychosomatic notion that the mind directly causes the physical illness.[5] However, Kissane et al. avoided this requirement in the selection of their criteria. There is a danger in attributing causation to the mind in such a direct manner, as although some interaction between mind and body occurs, it is not in a unidirectional manner but rather as a mutually reciprocal influence.[61] Nonetheless, mild and moderate states of demoralization do not necessarily impede the course of the medical illness. This is a central difference between the DCPR criteria and the one proposed by Kissane et al. Rather, with the simple conclusion that a stressor must be present, demoralization can be understood as arising in a context that challenges coping and adaptation. Thus, improved criteria might hold that demoralization can be diagnosed if a patient has a persisting mental state over two or more weeks as a result of a stressor event, with symptoms of 1) meaninglessness or purposelessness, 2) hopelessness or helplessness, 3) difficulty in coping and meeting expectations of self or others, and 4) feelings of failure or pointlessness that lead to a growing urge to stop trying, give up, withdraw, or consider ending life because of its lack of a worthwhile future.

Establishing consistency in diagnostic criteria will presume an accepted definition of demoralization, leading to an increased opportunity to empirically validate the syndrome across clinical settings and cultures.[3,6] Such empirical validation is necessary for recognition in future editions of diagnostic systems such as the DSM.[46]

Overall, this review demonstrates that demoralization presents in patients facing end-of-life and/or progressive disease. A key issue lies in identifying the clinical importance of demoralization and determining what is considered a normal vs. abnormal response. The current evidence in this field is limited regarding 1) the clinical factors that contribute to demoralization and 2) the need to further psychometrically refine the measurement of demoralization while clearly determining the best means for its assessment. Further research is required to improve the psychometric measurement of demoralization, possibly with IRT models, and obtain a clearer clinical picture of contributing factors to the development of demoralization. This review highlights that demoralization is not uncommon in patients with life-threatening diseases and thus confirms the importance of recognizing demoralization to optimally improve care.

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