



Frequency of demoralization and depression in cancer patients

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ARTICLE INFO

Keywords:

Demoralization
Cancer
Depression

1. Introduction/background

Demoralization is a mental state comprising low morale and a sense of poor coping, in which pessimism, helplessness and hopelessness can lead to loss of meaning and purpose in life. The concept of demoralization has been described as subjective incompetence coupled with distress in an environment of social isolation [1,2]. The patient is distressed by their “self-perceived incapacity to act at some minimal level according to some internalized standard in a specific stressful situation” [2]. This, coupled with breakdown in coping, leads the patient to the feeling of “being trapped, not knowing what to do and they become helpless” [3].

Various scales have been utilized to measure demoralization, including the Demoralization Scale (DS) [4], the Diagnostic Criteria for use in Psychosomatic Research [5], the Subjective Incompetence Scale [6] and the Short Demoralization Scale [7]. The DS is a 24-item scale, which has been psychometrically validated, translated into various languages and used in several different countries. With the DS, demoralization has been reported in patients with progressive disease (advanced cancer and neurologic disorders) [8], oophorectomized BRCA1/2 mutation carriers [9], and substance use with co-occurring psychiatric disorders [10]. Importantly, a systematic review of 2295 patients in an advanced cancer setting revealed a 13–18% prevalence of demoralization [4].

One key characteristic of depression is anhedonia, which has been associated with the patient's impaired ability to cope, decreased acceptance of treatment, decreased quality of life, and increased suicidality. In addition, cancer patients who are depressed have longer hospital stays and the use of antidepressants moderates that relationship [11].

On the surface, demoralization may not appear distinct from other dysphoric states. Yet, others have distinguished demoralization from

anhedonic depression and grief [12,13]. Studies have shown a strong positive correlation between depression and demoralization [14,15]. Notwithstanding, demoralization has been found to be divergent from anhedonic depression in moderate ranges of demoralization [15,16]. In addition, other studies found a subset of patients who are demoralized, but not depressed [17–19].

Importantly, demoralization has been found to be positively associated with suicidal ideation [18]. This is concerning since the risk of suicide is two to four times higher in patients with cancer than in the general population [20]. Beyond this, demoralization can also result in a desire for hastened death [3].

Recently the DS has been refined and revalidated into a 16-item, self-report of demoralization, which is named the Demoralization Scale 2 (DS-II) [14]. As of yet, the DS-II has not been studied beyond the validation studies done by Dr. Kissane's group in a cancer population and validation study of the Spanish DS-II by Belar's group [21]. It has been only studied in an inpatient Australian general palliative care unit with advanced cancer or advanced progressive disease of any type and in advanced cancer patients at Spanish Hospitals in Latin American and Spain in both the outpatient and inpatient settings. Recently, the DS-II has been adapted for use in women during the postnatal period [22].

In light of available data in the field, the primary objectives of this project were to determine (1) if there was an association between demoralization (DS-II) and depression (PHQ-9), and (2) if there were cohorts that did not conform to this association. We hypothesized that there would be a positive association between depression and demoralization. Further, we hypothesized that there would be a cohort exhibiting high levels of demoralization and low levels of depression. This report reflects the first attempt to use the DS-II to assess outpatients in an American psychiatric oncology clinic.

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2. Methods

This report includes adult patients ($N = 922$) with an active cancer diagnosis seen in an outpatient psychiatric oncology clinic. Patients were considered eligible for inclusion if they were 21 years or older and if they had an active cancer diagnosis. There were no other inclusion/exclusion criteria. Data shown were taken from a single visit (i.e., the first visit immediately after obtaining informed consent) per patient only; therefore, this was a cross-sectional, observational study design. A psychiatrist evaluated patients after receiving a consultation from another service at the cancer center, usually the primary specialized oncology team for psychosocial concerns. Patients are offered various therapeutic modalities including psychotherapy and/or psychotropic medications. The Institutional Review Board at institution approved the study and all patients provided written informed consent (Protocol # PA14-0265).

Assessment tools included the DS-II (scale 0–32) [14] and the PHQ-9 (scale 0–27) [23], which were used to assess demoralization and depression symptoms, respectively. The DS-II has been found to be psychometrically sound and is more simplified as compared to the DS to assess demoralization. Subscales of Meaning/Purpose and Distress/Coping can also be calculated along with total demoralization score [14]. Analyses of Demoralization Subscales, Distress/Coping and Meaning/Purpose were completed, but are not shown (these data can be provided upon request). The PHQ-9 is a widely used and well-validated assessment based on DSM-IV depression criteria [24]. Demographic variables included age, sex, race/ethnicity, relationship status (alone = separated, divorced, widowed; together = married, committed relationship) and cancer type.

The primary objectives for this report were addressed in the following ways: to determine if there was an association between demoralization and depression and a simple linear regression was performed. In addition, an ANOVA was conducted using DS-II groups as the categorical variable and PHQ-9 total scores as the continuous variable and using PHQ-9 groups as the categorical variable and DS-II total scores as the continuous variable. To determine if there were cohorts that did not conform to the association identified above, a pie chart was constructed identifying cohorts using key cut-offs for the PHQ-9 and DS-II. Specifically, for the PHQ-9 five key groups were compressed into 3; none and mild (scores 0–9) reclassified as Low, moderate (scores 10–14) reclassified as medium, and moderately severe and severe (scores 15–27) reclassified as High. Thresholds for the DS-II for this unique psychiatric sample were based on the distribution of percentile scores using the extreme group design model, “employing low scores as < 25th percentile, medium scores as 25th to 75th percentiles, and high scores as > 75th percentile” [25].

Data are presented as percentages or Mean \pm S.D. Significance was set at $p < .05$.

3. Results

In the current study, patients were 53.3 ± 13.2 (Mean \pm S.D.) years of age, mostly female (68%), Caucasian (76%), and most were in a committed relationship (62%) (Table 1). In addition, predominant cancer types included breast, hematological, and head & neck and gastrointestinal. Several demographic differences were noted, such that patients with higher DS-II scores were more likely to be younger (determined using a median split) ($F_{1,920} = 1837, p < .0001$), female ($F_{1,920} = 14.7, p < .0001$), and those with a relationship status of “alone” ($F_{1,914} = 24.5, p < .0001$). These demographic differences were included as co-variates for all subsequent analyses.

In this cohort, the average total DS-II score was 10.8 ± 8.0 and the average total PHQ-9 score was 9.5 ± 6.0 . To determine if there was an association between demoralization and depression a simple linear regression was performed. The outcomes showed a significant positive association between DS-II and PHQ-9 scores ($R = 0.72, p < .0001$;

Table 1

Demographics of sample ($N = 922$). URM underrepresented minorities (black or hispanic)

Demographics ($N = 922$)		
Age (years)		53.3 \pm 13.2
Sex	Male	32% ($N = 295$)
	Female	68% ($N = 627$)
Race/ethnicity	URM*	22% ($N = 203$)
	White	78% ($N = 719$)
Marital status	Alone	38% ($N = 350$)
	Together	62% ($N = 572$)
Cancer category	Breast	27% ($N = 253$)
	Hematological	22% ($N = 204$)
	Head, neck, & face	10% ($N = 95$)
	Gastrointestinal	10% ($N = 93$)
	Genitourinary	6% ($N = 57$)
	OB/gynecological	6% ($N = 54$)
Other	18% ($N = 166$)	

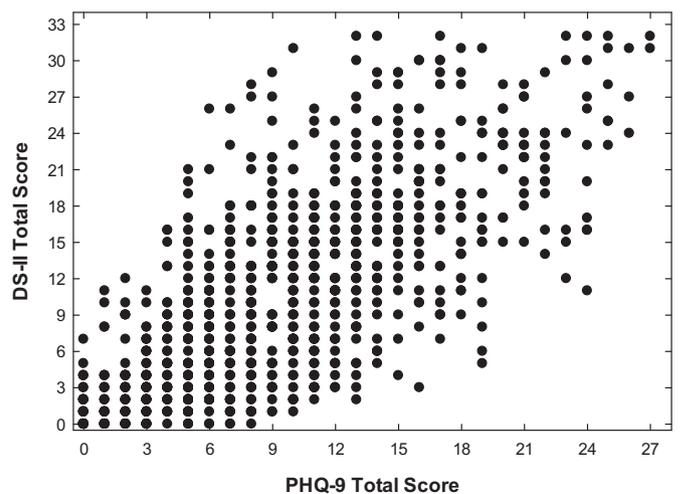


Fig. 1. Linear association between total DS-II scores (y-axis; scale 0–32) and PHQ-9 scores (x-axis; scale 0–27).

Fig. 1).

In this cohort, using the extreme groups design (Preacher 2015), DS-II categories of Low included scores 0–4 ($N = 257$), for Medium scores were 5–16 ($N = 451$), and for High scores were 17+ ($N = 214$).

An ANOVA was conducted using DS-II groups as the categorical variable and PHQ-9 total scores as the continuous variable, and the outcomes showed a significant linear increase in depression scores as a function of increasing severity of demoralization group ($F_{2,919} = 376.2, p < .0001$; Fig. 2A).

An ANOVA was also conducted using PHQ-9 groups as the categorical variable and DS-II total scores as the continuous variable and the outcomes showed a significant linear increase in demoralization scores as a function of increasing severity of depression group ($F_{4,917} = 218.1, p < .0001$; Fig. 2B).

To determine if there are cohorts that do not conform to the association identified above, a pie chart was constructed identifying cohorts using the PHQ-9 and DS-II (Fig. 3). Of the 9 groups identified, the majority fell along the expected association line with the largest cohorts being Low Depression + Low Demoralization ($N = 233$; 25.3%) and High Depression + High Demoralization ($N = 119$; 12.9%). The other predicted cohort would be individuals who fell in the middle range for one scale and high or low for the converse scale ($N = 474$; 51.4%). Of most interest, we identified a small cohort of individuals with Low Depression + High Demoralization ($N = 33$; 3.6%), but not High Depression + Low Demoralization ($N = 2$; 0.2%).

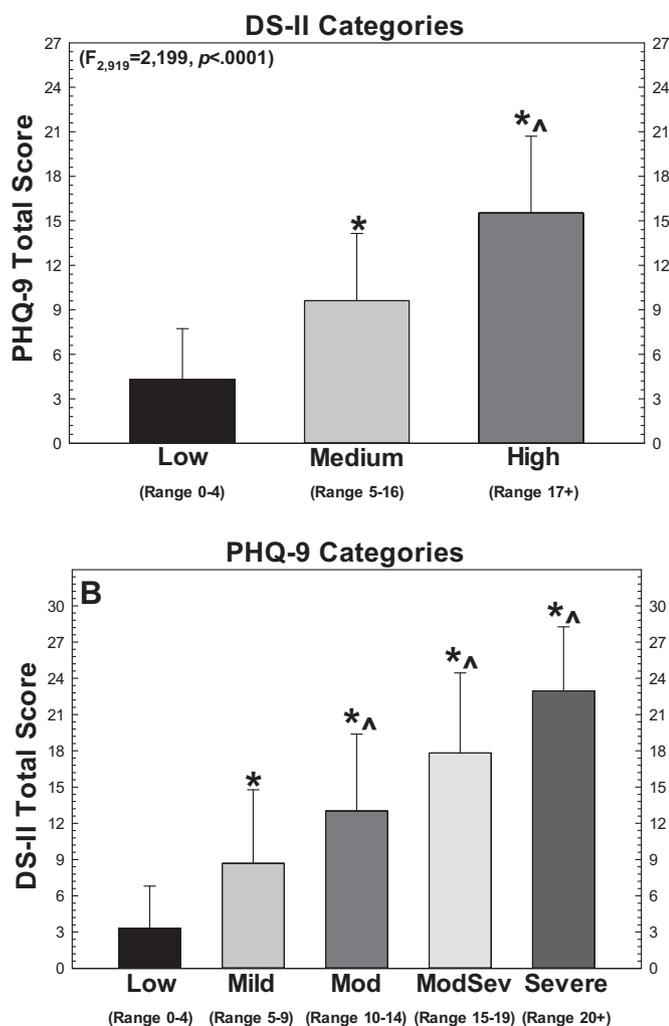


Fig. 2. A. ANOVA showing increased total depression scores (y-axis) as a function of demoralization group. *reflects significant difference versus Low DS-II, ^reflects significant difference versus Medium DS-II. B. ANOVA showing increased total demoralization scores (y-axis) as a function of depression group. *reflects significant difference versus Low PHQ-9, ^reflects significant difference versus next lowest PHQ-9 group.

4. Discussion

In conclusion, we report for the first time a strong positive correlation between depression scores and high demoralization scores as measured using the DS-II. Despite this correlation, we identified a small

cohort of individuals with Low Depression and High Demoralization (3.6%) that did not conform to the predicted association between these variables. We hypothesize that this cohort will be less likely to respond to antidepressants. Given that demoralization is associated with increased symptom burden [26] and defined as loss of meaning and purpose, we hypothesize that this group would likely respond best to meaning centered psychotherapies and symptom burden amelioration.

In the current study, the frequency of demoralization (scores 17+) was set to the upper quartile, with the actual group representing 23.1% of the sample. This figure is similar, albeit higher, to the prevalence of 13–18% shown in a systematic review of patients in an advanced cancer setting [4]. A possible difference in our report from previous work includes that our patients were in a different clinical and cultural setting. Specifically, our patients were examined in an outpatient psychiatric clinic, where one would expect a higher incidence of those with psychiatric/psychological illness as compared to a general oncology clinic or inpatient unit. Another obvious distinction was different versions of the demoralization scale were used in this report and in other reports cited. Further, our population was from the United States and there may be differences in frequencies of demoralization not accounted for by culture. In this review, prevalence scores from US populations were not shown so a comparison cannot be made.

As reported in other studies, we found a positive correlation between depression and demoralization [14,15,18,27]. Despite this finding, we did detect divergence between demoralization and depression. This finding coincides with reports by Grassi [17], Vehling [18] and Lee [19], all of whom identified the same cohort of patients who are demoralized but not depressed. Grassi and colleagues reported a much larger percentage (57.7%) of patients who were demoralized but not depressed [17]. The difference between that study and our investigation is likely a result of different demoralization cutoffs used. Further, distinct outcomes may be accounted for by considering differences in the DS and DS-II, and also by potential differences found in Italian vs. English scales. Overall, it is clear that this cohort exists and it warrants careful consideration as they may be different than those who are depressed and therefore may not respond to traditional treatments for depression. We recognize that the majority of patients in our clinic are treated with either psychotropics or psychotherapy, which could have influenced the level of demoralization and depression reported.

We found statistically higher demoralization scores in patients who were females, younger and not in a committed relationship. Previous studies reported relationships with sex, age and marital status and demoralization [4,19,28]. These results were not seen in original DS-II external validity study [14]. At present, our sample showed a linear association between total DS-II scores and PHQ-9 scores.

The approach to treatment of patients identified with demoralization can be approached in two ways dependent on if the patient has major depression versus distinct moderate demoralization or

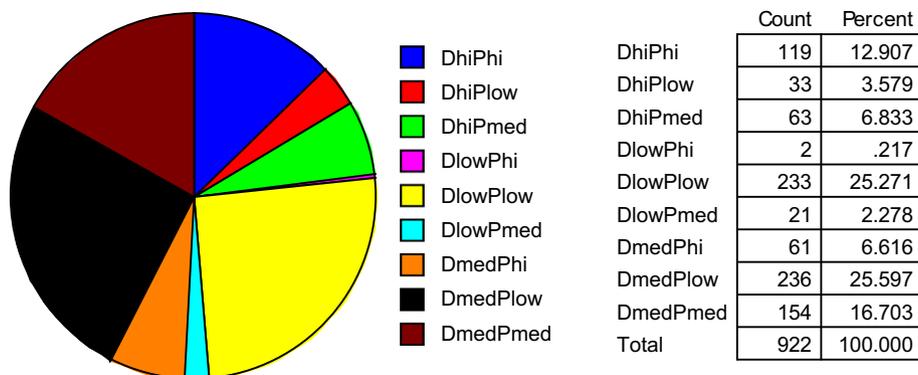


Fig. 3. Pie chart and accompanying table showing sample size and percentages of individuals that fall into one of 9 categories for high (Hi), medium (Med) and low (Low) depression (P; PHQ-9) and demoralization (D; DS-II).

adjustment disorder. In the latter, treatment with a meaning centered psychotherapy would be the approach to treating the patient. At the moment, there are several meaning centered psychotherapies such as Meaning Centered Psychotherapy [29], CALM therapy [30] or Legacy Therapy [31]. In patients with major depressive disorder with poor coping as a function of demoralization, treatment with psychopharmacologic intervention (SNRI, SSRI) would be prudent. After reassessment, augmentation with any of the above meaning centered psychotherapies should be considered. At current, there are no randomized controlled trials to see if these treatments are actually effective in amelioration of demoralization.

Li et al. [28] reported that family support and monthly income were protective factors in demoralization in cancer patients. Patients can be screened for demoralization using the DS-II and after proper assessment, risk reduction of demoralization should be made.

Limitations in the study included lack of data on stage of disease, employment status, religion, stress levels, type of psychotherapies used, or coping styles. This information would be useful and provide better understanding demoralization in this cohort. We recognize the fact that the screening instruments used are not diagnostic. We recognize the fact that the screening instruments used in this report are not diagnostic. In the future, therefore, we could use the Structured Clinical Interview for DSM-V to confirm neuropsychiatric diagnoses.

Future directions include determining the association of demoralization scores with various physical symptoms, cancer diagnosis, cancer stage and treatment phase. Bobevski et al. [22] used latent class analysis to determine probability of demoralization in psychopathology. They found an adjustment disorder category with features associated with moderate demoralization, and another anhedonic depression category was associated with severe demoralization. In the future, we plan to compare the demoralization categories with actual clinical diagnoses specified by clinicians. We are also interested in further characterizing the high demoralization and low depression cohort, in terms of demographic factors, cancer diagnosis, cancer stage, treatment phase, and other psychological factors. Further, we would like to study this group longitudinally to evaluate demoralization scores over time and to evaluate the effects of standard treatment versus Meaning Centered Psychotherapy.

Acknowledgements

Funding provided by the Hackett Family. The authors wish to thank Titilayo Olubajo and Nirmala Joseph for their expert assistance with data entry.

Conflicts of interest

The authors have no conflicts of interest to declare.

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