Demoralization among cancer patients in mainland China: validity of the Demoralization Scale(DS)

Lisha Deng[1], Ying Pang[1], Yi He[1], Yening Zhang[1], Richard Fielding[2], Lili Tang[1,] *.

1 Key Laboratory of Carcinogenesis and Translational Research (Ministry of Education/Beijing), Department of Psycho-Oncology, Peking University Cancer Hospital & Institute, Beijing, China

2 Centre for Psycho-oncology Research & Training, Division of Behavioral Sciences, School of Public Health, The University of Hong Kong, Hong Kong, China

*Corresponding author:

E-mail: tanglili_cpos@126.com(LLT)

Abstract

Demoralization, characterized by hopelessness, helplessness, and loss of meaning and purpose, reflects existential distress. The objectives is To assess the validity of a Mainland Chinese versions of the demoralization scale (MC-DS) for using with Mainland Chinese cancer patients. In-patients sequentially recruited from a specialist tertiary-level cancer hospital in Beijing between January 2016-April 2016 completed Demoralization Scale, (DS) Patient Health Questionnaire-9 (PHQ-9), Revised Life Orientation Test (CLOT-R), Beck Hopelessness Scale (BHS), and provided sociodemographic and clinical information. We determined DS factor structure and convergent and divergent validity. 296/424 (70.0%) participants reported mean DS score=30.42(SD=13.00). EFA identified 3-factors explaining 21.4%, 17.8%, and 10.6% respectively of observed variance. Respective Cronbach Alphas were 0.88, 0.84, and 0.64 (0.90 full-scale). Convergent was shown by PHQ-9 scores correlating with Factor 2 (r=0.606), and BHS and C-LOT-R scores correlating (r=0.632,r=0.407 respectively) with Factor 1. Dichotomizing demoralization (high >30, low≦30) cross-tabulated against PHQ-9 score (mood) scores revealed 47% of patients exceeded demoralization cut-off, 60% of whom were not depressed. Using mean value±SD indicated demoralization cutoffs at <17.4 (low), 17.4-43.4 (medium) and >43.4 (high). Overall 71% met criteria for medium demoralization, and 15% for high demoralization. Sixty percent of all medium demoralization patients were not depressed, but only 5% of high demoralization patients were not depressed. The conclusion is that the Mainland Chinese Demoralization Scale is useful for detecting

mild-to-moderate demoralization in cancer patients but at higher scores has poor specificity against depression.

(Word count: 239)

Key words: demoralization ; depression ; demoralization scale.

Introduction

Demoralization reflects existential distress [1-3], involving subjective incompetence [4], helplessness, hopelessness, worthlessness/meaninglessness, and desire for death [1, 2]. Diagnostic criteria require affective symptoms of existential distress, including hopelessness or loss of meaning and purpose in life; Attitudes reflecting pessimism, helplessness, sense of being trapped, personal failure, or lacking a worthwhile future; lacking motivation to cope differently, and; evidence of social alienation or isolation and lack of support. No major depressive or other psychiatric disorder constitutes the primary condition. Allowing for fluctuation in emotional intensity, these phenomena should persist for more than two weeks [5].

Both demoralization and depression, common in cancer [6], feature disrupted sleep and appetite, and suicidal ideation [7]. Demoralization is characterized by loss of purpose and meaning [5], depression by anhedonia [5,8]. Depressed patients struggle to experience anticipatory and consummatory pleasure, while Demoralized patients can still experience consummatory pleasure [9]. Hence, Grassi emphasized demoralization principally as existential suffering[10].

To measure demoralization syndrome a Demoralization Scale (DS) was developed [1] but scoring to classify demoralization is uncertain. Two methods have been proposed: using total score cut-off at 30 [1], or the mean value plus one standard deviation (M+1s.d.) [11].

The DS has been recently updated to improve ease of use [12] but ongoing disagreement about the divergence between demoralization and depression, and the appropriate cutoff values remain, generating methodological variability, which decreases DS diagnostic utility, so resolution is needed.

Currently, most relevant studies address English-speaking populations, though a Taiwanese Mandarin Chinese translation of the DS was validated [13]. We report a revalidation of the DS in Mainland China and compared classifications using competing methods.

Methods

Participants

Following ethics committee approval (2015YJ03), in-patients at a tertiary cancer center in Northern China were recruited between January 2016-April 2016 from departments specializing in alimentary, respiratory, breast, gynecological, lymphatic, genitor-urinary and musculoskeletal system malignancies. Patients 18 years or older, willing to sign informed consent and able to complete assessments were eligibile. Overall 296/424 (70.0%) of patients approached completed questionnaires.

Assessments

Demoralization Scale (DS): Simplified characters were substituted for the traditional characters in the validated Chinese version [13]. The DS assesses status over the preceding 2 weeks. The original 24 items (α=0.94) constitute five factors: loss of meaning and purpose (α=0.87), dysphoria (α=0.85), disheartenment (α=0.89), helplessness (α=0.84), and sense of failure (α=0.71) [1]. The 5-point likert-type response scale is scored from, 0 (never), through to 4 (all the time) [11]. Five items are reverse scored, item scores are summed, higher scores reflecting greater demoralization.

Patient Health Questionnaire-9: The nine item PHQ-9 [14] measured depression over the prior two-weeks, using 4-point likert-type responses assessing symptom duration from 0 (“not at all”), to 3 (“nearly every day”) yielding a total score between 0-27. A summed score >=10 constitutes criterion for a diagnosis of depression. Scale α coefficients range between 0.79-0.82.

Beck Hopelessness Scale [15]: Twenty self-report items measure hopelessness using binary (“yes”/“no”) responses giving a total scores range from 0-20. Total scores of 0-3 reflect “minimal”, 4-8 “mild”, 9-14 “moderate”, and above 14 “severe” hopelessness. Scale α coefficient range between 0.85-0.93.

Chinese Life Orientation Test-Revised (C-LOT-R): The Mainland Chinese version [16] comprises six items scored on 5 point likert-type scales. The balance of scores indicates an optimistic, neutral or pessimistic orientation towards future outcomes.

Social and clinical data were gathered on age, gender, education, ethnicity, occupation, marital status and diagnosis, time since diagnosis and treatment.

Procedure

Procedures and explanations were piloted among 30 in-patients. Subsequently eligible patients were identified from ward lists and approached for informed consent. Those agreeing were then given an introduction on self-completion of the instruments. All scales were checked and missing data were clarified with patients and completed following investigator clarifications.

Data analysis

Data were coded and doubly entered independently by two experimenters respectively using EpiData 3.0 then checked and cleaned. After sample characteristics, frequencies and proportions descriptions, principal components analysis (PCA)-based Exploratory Factor Analysis (EFA) clarified the underlying factor structure of the DS. The number of factors was not pre-specified. Factors whose eigenvalue **>** 1 were extracted and retained, and with scree plot analysis informed the number of factors extracted. Parsimony guided interpretation. Independent T-test then compared demoralization and non-demoralization groups. All proportions are reported as whole numbers.

Results

296/424 (70.0%) of eligible patients participated. Mean age was 50.3 years, (SD=12.6, range 18 to 83). Females comprised 192/296 (64.9%) of the sample. Most

(263/296, 89%) reported Han ethnicity and no religion (250/296, 84%). Most (271/296, 92%) were married and educated to high school (72/296 patients, 24%), junior high school (67/296, 23%) or university (63/296 patients, 21%) levels. Participants (73/296, 25%), were retired, farmers (58, 20%), professionals (41, 14%) or held other occupations (39, 13%). Most reported monthly incomes of =<¥3000 (US$450) (94, 32%), ¥3001-¥5000 (83, 30%) and ¥5001 or more (52, 18%). Breast (82/296, 28%), and respiratory tract (66/296, 22%) tumours were most common. Mean illness duration was 2.1 years, (SD 3.2 years, range 0-19.6 years), and 1.0 years since first cancer diagnosis, (SD 1.4 years, range 0-9.7 years).

Demoralization scale

Mean DS score was 30.42 (SD=13.00, range 0-80), close to scores reported by Kissane et al (30.82, SD=17.73) [1] and Mehnert et al (29.80, SD=10.41, range 2-61) [17], but higher than Mullane et al's (19.94, SD=14.62, range 1-61) [11].

Factor structure

A 5-factor solution provided no cleaner item-factor separation than a 4-factor solution, with four cross-loading items (items 5, 11, 22, 23). However, with 4 factors, the factor loading for item 10 was smaller than 0.4, so this was deleted, and the PCA repeated. Items 22 and 23 continued to cross-load equally on factors 1 and 2. After deleting item 22 and 23, and repeating the PCA the 4-factor solution showed no cross-factor loadings for other items. In contrast a 3-factor solution provided clean

155 item separation without further item deletion after deleting items 10(low factor
156 loading), 22(cross-load) , 23(cross-load) and so was chosen as most parsimonious.
157 Table 1 shows the final 3-factor solution, which explained 49.8% of observed total
158 variance, attributable to factors 1 to 3 at 21.4%, 17.8%, and 10.6% respectively.

Table 1. Principal components analysis of the Demoralization Scale (items 10, 22, and 23 deleted)

Item number	Item content	factor1	factor2	factor3
14	Life is no longer worth living.	.756		
4	My role in life has no purpose.	.741		
7	No one can help me.	.714		
3	There is no purpose to the activity in my life.	.704		
2	My life seems to be pointless.	.668		
8	I feel that I cannot help myself.	.659		
9	I feel hopeless.	.630		
20	I would rather not be alive.	.595		
5	I no longer feel emotionally in control.	.461		
15	I tend to feel hurt easily.		.703	
21	I feel sad and miserable.		.697	
16	I am angry about a lot of things		.692	
11	I feel irritable.		.666	

18	I feel distressed about what is happening to me.	.641	
13	I have a lot of regret about my life.	.612	
24	I feel trapped by what is happen to me.	.605	
19	I am a worthwhile person.		.627
17	I am proud of my accomplishments.		.601
12	I cope fairly with life.		.601
1	There is a lot of value in what I can offer.		.595
6	I am in good spirits.		.553

Extraction method: Principal Component Analysis

Rotation method: Varimax with Kaiser Normalization

Rotation converged in 7 iterations.

Factor 1 concatenated the original DS "Loss of meaning and purpose" and "Helplessness" subscales [1]. Factor 2 corresponds to the original "Dysphoria" subscale plus the "disheartenment" subscale minus item 6 (In good spirits), item 10 (Feel guilty), item 22 (Feel discouraged about life-deleted) and item 23 (Feel isolated or alone-deleted). Factor 3 corresponds to the original "Sense of failure" factor plus item 6 (In good spirits). These three factors make good intuitive sense, capturing Despondency, Distress and Self-worth, and were so named.

Cronbach's α of the total demoralization scale was 0.90, and Cronbach's α for

172 factors 1 to 3 were 0.88, 0.84, and 0.64 respectively, indicating good (Factors 1 & 2)
173 to acceptable (Factor 3) item scalability. Subscale intercorrelations were 0.606
174 between Factor 1 and Factor 2, 0.489 between Factor 2 and Factor 3 and 0.478
175 between Factor 1 and Factor 3 (Table 2).

176 Table 2: Intercorrelation among subscales of Demoralization Scale

subscale	Factor 1	Factor 2	Factor 3
Factor 1	1	0.606[a]	0.478[a]
Factor 2		1	0.489[a]
Factor3			1

177 [a] : $p < 0.01$ for all values.

178 Mainland Chinese DS (MC-DS) subscales positively correlated with PHQ-9, BHS
179 and negatively with the C-LOT-R. PHQ-9 score correlated most strongly with MC-DS
180 Factor 2 (r= 0.606). The BHS correlated most strongly with MC-DS Factor 1
181 (r=0.632). The C-LOT-R correlated most strongly with MC-DS Factor 1 (r= -0.407)
182 (Table 3).

183 Table 3: Correlations between DS subscales and PHQ-9, BHS, and CLOT.

	Factor 1	Factor 2	Factor 3
PHQ-9	0.572[a]	0.606[a]	0.352[a]
BHS	0.632[a]	0.546[a]	0.428[a]
CLOT	-0.407[a]	-0.404[a]	-0.389[a]

184 *a: p< 0.01 level(2-tailed).*

185 *b: p< 0.05 level(2-tailed)*

PHQ-9: Patient Health Questionnaire -9; BHS: Beck Hopelessness Scale; C-LOT-R: Mainland Chinese Revised Life Orientation Test; MCMQ Medical Coping Modes Questionnaire.

Two approaches were used to compute the MC-DS demoralization cutoff values. First, dichotomization at the mean of 30 (> 30 high, ≤30 low demoralization) [1], then by trichotomization using score tertiles [11]. For the latter, given our observed mean of 30.42, SD=13.00, MC-DS total score was divided into tertiles of low demoralization (<17.4), medium demoralization (17.4-43.4) and high demoralization (>43.4). Table 4 shows the resulting classifications. When dichotomized at mean score 47% of the sample met the demoralization criterion. In contrast, trichotomized cutoff values classified 71% of all patients as having medium demoralization and 15% of all patients as having high demoralization.

Table 4 Cross-tabulation of Demoralization Scale (DS) and Patient Health Questionnaire -9(PHQ-9)

	DS (category=1[a])		DS (category 2[b])			Total
PHQ-9	Low (≤30)	High (> 30)	Low (< 17.4)	Medium (17.4-43.4)	High (> 43.4)	
Not Depressed(< 10)	153 (51.7%)	83(28.0%)	42(14.2 %)	179(60.5 %)	15(5.1%)	236(79.73 %)

Depressed (≥10)	4 (1.4%)	56(18.9%)	0(0%)	31(10.5 %)	29(9.8%)	60(20.3%)
Total	157(53.0 %)	139 (47.0%)	42(14.2 %)	210(70.9 %)	44(14.9 %)	296 (100%)

Category 1: mean 30.42 dichotomization; Category 2 tertiles based on mean and SD= 13.0.

The ability of the MC-DS to discriminate between demoralization and depression determines its utility. Of 296 respondents, 60/296 (20%) achieved PHQ-9 scores indicating likely depression. Of these 56 (93%) also met the demoralization criterion when dichotomizing; when trichotomizing all 60 (100%) met medium- or high-demoralization criteria. Among those trichotomized as low demoralization only 1-in-40 were likely depressed (false negative). Conversely, dichotomization identified 47% of participants as demoralized, 19% of who were also depressed but, of the 53% not classified as demoralized, only 1.4% were depressed. This suggests that depressed individuals in this population will almost always attract a Demoralization diagnosis using these criteria and instrument.

Of respondents identified as demoralized, approximately 1-in-5 were also depressed, irrespective of the classification method used. Using trichotomization, 15% of medium- and 66% of high-Demoralized cancer patients were also likely depressed, but none of the 42 respondents in the low demoralization category were depressed. Trichotomization shows that most demoralized patients fall within 1 S.D. either side

of the sample mean, whereas most depressed patients score above the sample mean on the DS. Those scoring higher than DS mean+1 S.D have a 2-in-3 chance of being depressed, while those scoring lower than DS mean-1 S.D. will not be depressed.

Discussion

Among 296 Chinese cancer in-patients the adapted MC-DS generated a mean score=30.42, SD=13.00, similar to reported Australian [1] German samples [17], but higher than an Irish sample [11].

Kissane et al's [1] 5-factor solution adopted for Lee et al's Taiwanese validation [2] did not readily fit the Mainland Chinese sample reported herein. Several items cross-loaded on multiple factors and another (item 10, "feeling guilty") was ejected for low loading. After testing 5-, 4-, and 3-factor solutions, and requiring deletion of three items a 3-factor model proved most parsimonious. Two deleted items (feeling discouraged/alone) do not discriminate adequately in the highly group-oriented Chinese culture as Confucian moral codes dictate the sick be cared for and protected by their families. Families support patients and often diagnosis is withheld to maintain hope, reflecting beliefs that loss of hope precipitates rapid deterioration and premature death.

This 3-factor solution accounted for 49.8% of observed score variance and compares sensibly with the original 5-factor structure [1]. Factor 1 concatenated Kissane et al's "helplessness" and "loss of meaning and purpose" factors, into a factor named "Despondency" that captures the sense of this item cluster. Our Factor 2,

241 labelled “Distress” captures Kissane et al ’s “dysphoria and disheartenment” and
242 elements of “sense of failure” factors reflecting hurt, anger, frustration and regret. The
243 remainder of “sense of failure” loaded on our Despondency factor. Our final factor 3
244 clearly captures items addressing perceived “Self-worth” and is labeled as such. These
245 three factors we feel provide a good representation of demoralization within a
246 different cultural context. Our Despondency factor did not differentiate what Kissane
247 et al [1] called “loss of meaning and purpose” from “helplessness”, suggesting a core
248 element of demoralization. Similarly our Distress factor did not differentiate
249 “dysphoria” from “disheartenment” suggesting a degree of conceptual commonality.
250 Mood scores (PHQ-9) positively and strongly correlated with all three factors, less
251 so with self-worth and more so with Despondency, whereas hopelessness scores
252 (BHS), as expected, also correlated most with factor 1, Despondency.
253 Both existing classification cut-offs indicate that as DS scores increase above the
254 mean, cancer patients are increasingly likely to be depressed (as well as demoralized)
255 and the utility of the scale becomes more questionable. The discriminant validity
256 (know case method) of the MC-DS declines as scores increase indicating the
257 instrument is most useful for excluding demoralization in cancer patients scoring
258 below the original cut-off [1].
259 When using the recommended dichotomization scoring method [1], 47% patients
260 were “demoralized”, while of patients not depressed on PHQ-9 scores 28% scored
261 high demoralization. That substantially exceeds the 7% -14% identified by Kissane et
262 al [1] and the 19.6% identified by Mehnert et al [17]. In contrast, with the

trichotomization method [11] a proportion, 71% of the present sample, comparable to the 72.1% reported by Mullane et al [11] were classified as having medium demoralization, while 15% met the criterion for high demoralization, approximating the 13.4% reported by Mullane et al [10]. A higher proportion of 60% met the criterion for medium demoralization without depression, slightly higher than the 51.5% reported by Mullane et al [11], and 5% of these Chinese patients identical to Mullane et al's 5.2% met the criteria for high demoralization without depression. The similarity of the classification proportions in this Chinese and Mullane's Irish sample are noteworthy. This suggests the trichotomization scoring method may be more robust to sample variability. Clarification of this point is needed.

Our results support concurrent validity, but not divergent validity of the DS. At higher values, the DS poorly differentiates demoralization from depression. This is consistent with the results of Mullane, et al [11] and Mangelli et al [18], but not Kissane et at [1] Mehnert, et al [17] and Hung et al [13]. The scale in its current form does not readily differentiate demoralization from depression in this population, except at low levels of demoralization, and below scores of mean-1s.d. where demoralized patients are unlikely to be depressed.

This study has several limitations including, patient recruitment from only one cancer center, though this should not make a large difference in this type of study. Using only inpatients may bias the apparent prevalence of demoralization reported in this study. However, again, determining the absolute prevalence of demoralization was not the purpose of this study and so this, in fact, is a strength because it increases

the power of the study to differentiate between demoralized and depressed.

Demoralization was measured in cancer patients, but this says nothing about whether the demoralization scale would fit other populations in China, for example those with schizophrenia, heart failure or end-stage renal disease. Otherwise, the sample size was adequate for the number of scale items and the analysis was performed as an EFA and not a CFA, thereby avoiding the assumptions underpinning the latter.

(Word count: 2,296)

Acknowledgments

We thank the participation of patients in Beijing Cancer Hospital.

References

1. Kissane DW, Wein S, Love A, Lee XQ, Kee PL, Clarke DM. The Demoralization Scale: a Report of Its Development and Preliminary Validation. J Palliat Care 2004;20(4):269-76.

2. Lee CY, Fang CK, Yang YC, Liu CL, Leu YS, Wang TE, et al. Demoralization syndrome among cancer outpatients in Taiwan. Support Care Cancer 2012 Oct;20(10):2259-67.

3. Robinson S, Kissane DW, Brooker J, Burney S. A Systematic Review of the Demoralization Syndrome in Individuals With Progressive Disease and Cancer: A

307 Decade of Research. J Pain Symptom Manage 2015 Mar;49(3):595-610.

308 4. Jacobsen JC, Vanderwerker LC, Block SD，Friedlander RJ. Depression and

309 demoralization as distinct syndromes: Preliminary data from a cohort of advanced

310 cancer patients. Indian J Palliat Care 2006;12(1):8-15.

311 5. Kissane DW, Clarke DM and Street AF. Demoralization syndrome--a relevant

312 psychiatric diagnosis for palliative care. J Palliat Care 2001;17(1):12-21.

313 6. Fang CK, Chiu YJ, Yeh PC, Pi SH, Li YC. Association among depression,

314 demoralization, and posttraumatic growth in cancer patient preliminary study.

315 Asia-Pac J Clin Oncol 2012;8(Suppl.3):220–358

316 7. Griffith JL, Gaby L. Brief Psychotherapy at the Bedside: Countering

317 Demoralization From Medical Illness. Psychosomatics 2005 Mar-Apr;46(2):109-16.

318 8. Angelino A, Treisman G. Major depression and demoralization in cancer patients:

319 diagnostic and treatment considerations. Support Care Cancer 2001;9:344-349.

320 9. de Figueiredo JM. Depression and Demoralization: Phenomenologic and Research

321 Perspectives. Compr Psychiatry 1993Sep-Oct;34(5):308-11.

322 10. Grassi L, Nanni MG. Demoralization syndrome: new insights in psychosocial

323 cancer care. Cancer 2016 Jul;122(14):2130-3.

324 11. Mullane M, Dooley B, Tiernan E, Bates U. Validation of the Demoralization

325 Scale in an Irish advanced cancer sample. Palliat Support Care 2009 Sep;7(3): 323-30.

326 12. Robinson S, Kissane DW, Brooker J, Michael N, Fischer J, Franco M, et al.

327 Refinement and revalidation of the demoralization scale: the DS-II-internal validity.

328 Cancer 2016 Jul;122(14):2251-9.

329 13. Hung HC, Chen HW, Chang YF, Yang YC, Liu CL, Hsieh RK. Evaluation of the
330 reliability and validity of the Mandarin Version of Demoralization Scale for cancer
331 patients. J Intern Med Taiwan 2010;21(6):427–35. Chinese.
332 14. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report
333 version of the PRIME-MD: the PHQ primary care study. JAMA 1999
334 Nov;282(18):1737-44.
335 15. Beck AT, Weissman A, Lester D, Trexler L. The measurement of pessimism: the
336 hopelessness scale. J Consult Clin Psychol 1974 Dec;42(6):861–5.
337 16. Lai JC, Yue XD. Measuring optimism in Hong Kong and Mainland Chinese with
338 the Revised Life Orientation Test. Pers Individ Dif 2000 Apr;28(4):781-96.
339 17. Mehnert A, Vehling S, Hocker A, Lehmann C, Koch U. Demoralization and
340 Depression in Patients With Advanced Cancer: Validation of the German Version of
341 the Demoralization Scale. J Pain Symptom Manage 2011 Nov;42(5):768-76.
342 18. Mangelli L, Fava GA, Grandi S, et al. Assessing demoralization and depression in
343 the setting of medical disease. J Clin Psychiatry 2005 Mar;66(3):391-4.
344