

1 ***Demoralization among cancer patients in mainland China: validity of the***

2 ***Demoralization Scale(DS)***

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23 **Abstract**

24 Demoralization, characterized by hopelessness, helplessness, and loss of meaning
25 and purpose, reflects existential distress. The objectives is To assess the validity of a
26 Mainland Chinese versions of the demoralization scale (MC-DS) for using with
27 Mainland Chinese cancer patients. In-patients sequentially recruited from a specialist
28 tertiary-level cancer hospital in Beijing between January 2016-April 2016 completed
29 Demoralization Scale, (DS) Patient Health Questionnaire-9 (PHQ-9), Revised Life
30 Orientation Test (CLOT-R), Beck Hopelessness Scale (BHS), and provided
31 sociodemographic and clinical information. We determined DS factor structure and
32 convergent and divergent validity. 296/424 (70.0%) participants reported mean DS
33 score=30.42(SD=13.00). EFA identified 3-factors explaining 21.4%, 17.8%, and
34 10.6% respectively of observed variance. Respective Cronbach Alphas were 0.88,
35 0.84, and 0.64 (0.90 full-scale). Convergent was shown by PHQ-9 scores correlating
36 with Factor 2 ($r=0.606$), and BHS and C-LOT-R scores correlating ($r=0.632, r=0.407$
37 respectively) with Factor 1. Dichotomizing demoralization (high >30 , low ≤ 30)
38 cross-tabulated against PHQ-9 score (mood) scores revealed 47% of patients
39 exceeded demoralization cut-off, 60% of whom were not depressed. Using mean
40 value \pm SD indicated demoralization cutoffs at <17.4 (low), 17.4-43.4 (medium)
41 and >43.4 (high). Overall 71% met criteria for medium demoralization, and 15% for
42 high demoralization. Sixty percent of all medium demoralization patients were not
43 depressed, but only 5% of high demoralization patients were not depressed. The
44 conclusion is that the Mainland Chinese Demoralization Scale is useful for detecting

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

47 (Word count: 239)

48 Key words: demoralization ; depression ; demoralization scale.

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51 **Introduction**

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

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

67 To measure demoralization syndrome a Demoralization Scale (DS) was developed
68 [1] but scoring to classify demoralization is uncertain. Two methods have been
69 proposed: using total score cut-off at 30 [1], or the mean value plus one standard
70 deviation (M+1s.d.) [11].

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

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

79

80 **Methods**

81 **Participants**

82 Following ethics committee approval (2015YJ03), in-patients at a tertiary cancer
83 center in Northern China were recruited between January 2016-April 2016 from
84 departments specializing in alimentary, respiratory, breast, gynecological, lymphatic,
85 genitor-urinary and musculoskeletal system malignancies. Patients 18 years or older,
86 willing to sign informed consent and able to complete assessments were eligible.

87 Overall 296/424 (70.0%) of patients approached completed questionnaires.

88 **Assessments**

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

97 Patient Health Questionnaire-9: The nine item PHQ-9 [14] measured depression
98 over the prior two-weeks, using 4-point likert-type responses assessing symptom
99 duration from 0 (“not at all”), to 3 (“nearly every day”) yielding a total score between
100 0-27. A summed score ≥ 10 constitutes criterion for a diagnosis of depression. Scale
101 α coefficients range between 0.79-0.82.

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

106 Chinese Life Orientation Test-Revised (C-LOT-R): The Mainland Chinese version
107 [16] comprises six items scored on 5 point likert-type scales. The balance of scores
108 indicates an optimistic, neutral or pessimistic orientation towards future outcomes.

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

111

112 **Procedure**

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

118

119 **Data analysis**

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

129

130 **Results**

131 296/424 (70.0%) of eligible patients participated. Mean age was 50.3 years,
132 (SD=12.6, range 18 to 83). Females comprised 192/296 (64.9%) of the sample. Most

133 (263/296, 89%) reported Han ethnicity and no religion (250/296, 84%). Most
134 (271/296, 92%) were married and educated to high school (72/296 patients, 24%),
135 junior high school (67/296, 23%) or university (63/296 patients, 21%) levels.
136 Participants (73/296, 25%), were retired, farmers (58, 20%), professionals (41, 14%)
137 or held other occupations (39, 13%). Most reported monthly incomes of \leq ¥3000
138 (US\$450) (94, 32%), ¥3001-¥5000 (83, 30%) and ¥5001 or more (52, 18%). Breast
139 (82/296, 28%), and respiratory tract (66/296, 22%) tumours were most common.
140 Mean illness duration was 2.1 years, (SD 3.2 years, range 0-19.6 years), and 1.0 years
141 since first cancer diagnosis, (SD 1.4 years, range 0-9.7 years).

142

143 **Demoralization scale**

144 Mean DS score was 30.42 (SD=13.00, range 0-80), close to scores reported by
145 Kissane et al (30.82, SD=17.73) [1] and Mehnert et al (29.80, SD=10.41, range 2-61)
146 [17], but higher than Mullane et al's (19.94, SD=14.62, range 1-61) [11].

147

148 **Factor structure**

149 A 5-factor solution provided no cleaner item-factor separation than a 4-factor
150 solution, with four cross-loading items (items 5, 11, 22, 23). However, with 4 factors,
151 the factor loading for item 10 was smaller than 0.4, so this was deleted, and the PCA
152 repeated. Items 22 and 23 continued to cross-load equally on factors 1 and 2. After
153 deleting item 22 and 23, and repeating the PCA the 4-factor solution showed no
154 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

159 *Extraction method: Principal Component Analysis*

160 *Rotation method: Varimax with Kaiser Normalization*

161 *Rotation converged in 7 iterations.*

162

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

170

171 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)

186 *PHQ-9: Patient Health Questionnaire -9; BHS: Beck Hopelessness Scale; C-LOT-R:*

187 *Mainland Chinese Revised Life Orientation Test; MCMQ Medical Coping Modes*

188 *Questionnaire.*

189

190 Two approaches were used to compute the MC-DS demoralization cutoff values.

191 First, dichotomization at the mean of 30 (> 30 high, ≤ 30 low demoralization) [1],

192 then by trichotomization using score tertiles [11]. For the latter, given our observed

193 mean of 30.42, SD=13.00, MC-DS total score was divided into tertiles of low

194 demoralization (< 17.4), medium demoralization (17.4-43.4) and high demoralization

195 (> 43.4). Table 4 shows the resulting classifications. When dichotomized at mean

196 score 47% of the sample met the demoralization criterion. In contrast, trichotomized

197 cutoff values classified 71% of all patients as having medium demoralization and 15%

198 of all patients as having high demoralization.

199 Table 4 Cross-tabulation of Demoralization Scale (DS) and Patient Health

200 Questionnaire -9(PHQ-9)

PHQ-9	DS (category=1 ^a)		DS (category 2 ^b)			Total
	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	4 (1.4%)	56(18.9%)	0(0%)	31(10.5	29(9.8%)	60(20.3%)
(≥10)				%)		
Total	157(53.0	139	42(14.2	210(70.9	44(14.9	296
	%)	(47.0%)	%)	%)	%)	(100%)

201 *Category 1: mean 30.42 dichotomization; Category 2 tertiles based on mean and*

202 *SD= 13.0.*

203

204 The ability of the MC-DS to discriminate between demoralization and depression

205 determines its utility. Of 296 respondents, 60/296 (20%) achieved PHQ-9 scores

206 indicating likely depression. Of these 56 (93%) also met the demoralization criterion

207 when dichotomizing; when trichotomizing all 60 (100%) met medium- or

208 high-demoralization criteria. Among those trichotomized as low demoralization only

209 1-in-40 were likely depressed (false negative). Conversely, dichotomization identified

210 47% of participants as demoralized, 19% of who were also depressed but, of the 53%

211 not classified as demoralized, only 1.4% were depressed. This suggests that depressed

212 individuals in this population will almost always attract a Demoralization diagnosis

213 using these criteria and instrument.

214 Of respondents identified as demoralized, approximately 1-in-5 were also

215 depressed, irrespective of the classification method used. Using trichotomization, 15%

216 of medium- and 66% of high-Demoralized cancer patients were also likely depressed,

217 but none of the 42 respondents in the low demoralization category were depressed.

218 Trichotomization shows that most demoralized patients fall within 1 S.D. either side

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

222

223 **Discussion**

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

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

237 This 3-factor solution accounted for 49.8% of observed score variance and
238 compares sensibly with the original 5-factor structure [1]. Factor 1 concatenated
239 Kissane et al's "helplessness" and "loss of meaning and purpose" factors, into a factor
240 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

263 trichotomization method [11] a proportion, 71% of the present sample, comparable to
264 the 72.1% reported by Mullane et al [11] were classified as having medium
265 demoralization, while 15% met the criterion for high demoralization, approximating
266 the 13.4% reported by Mullane et al [10]. A higher proportion of 60% met the
267 criterion for medium demoralization without depression, slightly higher than the
268 51.5% reported by Mullane et al [11], and 5% of these Chinese patients identical to
269 Mullane et al's 5.2% met the criteria for high demoralization without depression. The
270 similarity of the classification proportions in this Chinese and Mullane's Irish sample
271 are noteworthy. This suggests the trichotomization scoring method may be more
272 robust to sample variability. Clarification of this point is needed.

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

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

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

286 Demoralization was measured in cancer patients, but this says nothing about

287 whether the demoralization scale would fit other populations in China, for example

288 those with schizophrenia, heart failure or end-stage renal disease. Otherwise, the

289 sample size was adequate for the number of scale items and the analysis was

290 performed as an EFA and not a CFA, thereby avoiding the assumptions underpinning

291 the latter.

292

293 (Word count: 2,296)

294

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297

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