Med & Health Jun 2021; 16(1): 108-122 https://doi.org/10.17576/MH.2021.1601.10

ORIGINAL ARTICLE

Demoralisation in Cancer Patients: The Association with Distress, Depression and Positive Emotion

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ABSTRAK

Pesakit kanser mengalami tekanan dan kemurungan yang tinggi. Pemahaman tentang hubungan psikologinya seperti demoralisasi dan emosi positif membantu dalam pengurusan keadaan ini. Objektif kajian adalah untuk mengkaji hubungan antara demoralisasi dan emosi positif, iaitu emosi yang menyenangkan seperti kegembiraan, kebanggaan, kepuasan dan sayang, dengan kemurungan dan tekanan bagi pesakit kanser. Faktor yang berkaitan dengan sosiodemografi dan klinikal juga dikaji. Kajian ini merekrut 178 pesakit kanser dari hospital universiti tempatan. Mereka dinilai menggunakan skala "Demoralization Scale" versi Bahasa Melayu (DS-M), skala "Positive Emotion Rating Scale" (PERS), skala "Centre for Epidemiologic Studies Depression Scale" (CESD) dan skala "Distress Thermometer". Umur rata-rata subjek adalah 53.6 ± 16.51 tahun, dengan 24% dari mereka berada pada tahap lanjut kanser. Hampir 38% subjek mengalami demoralisasi. Daripada jumlah itu, 61.2% mengalami kemurungan, 52.2% mempunyai emosi positif rendah, dan 68.7% mengalami tekanan. Demoralisasi berkorelasi positif dengan kemurungan ($r=0.78$, $p<0.01$) dan tahap tekanan ($r=0.64$, $p<0.01$) tetapi berkorelasi negatif dengan emosi positif ($r=-0.69$, $p<0.01$). Kesimpulannya, demoralisasi sangat lazim dan berkaitan dengan kemurungan dan tekanan bagi pesakit barah. Penilaian dan pengesanan awal demoralisasi dalam kalangan pesakit barah harus mendapat perhatian yang lebih. Kajian lanjut mengenai pengurusan keadaan ini diperlukan.

Kata kunci: demoralisasi, emosi positif, kanser, kemurungan, tekanan

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ABSTRACT

Cancer patients experience a high level of distress and depression. The understanding of its psychological correlates such as demoralisation and positive emotion helps in the management of these conditions. The study objectives are to examine the correlation between demoralisation and positive emotion, defined as discrete pleasant emotions, such as joy, pride, contentment or love, with depression and distress in cancer patients. The sociodemographic and clinical associated factors are also studied. This cross-sectional study recruited 178 cancer patients from a local university hospital. They were assessed using the Malay versions of the Demoralization Scales (DS-M), Positive Emotion Rating Scale (PERS), Centre for Epidemiologic Studies Depression (CESD) Scale, and Distress Thermometer. The mean age of the subjects was 53.6 $\pm$ 16.51 years old, with 24% of them were in the advanced stage of cancer. Almost 38% of the subject were demoralised. Of them, 61.2% were depressed, 52.2% had low positive emotion, and 68.7% were distressed. Demoralisation was positively correlated with depression ($r=0.78$, $p<0.01$) and distress level ($r=0.64$, $p<0.01$) but negatively correlated with positive emotion ($r=-0.69$, $p<0.01$). In conclusion, demoralisation was highly prevalent and strongly associated with depression and distress in cancer patients. Assessment and early detection of demoralisation among cancer patients should receive more attention. Future studies on the management of this condition are needed.

Keywords: cancer, demoralisation, depression, distress, positive emotion

INTRODUCTION

The Malaysian National Cancer Registry Report showed that more than 100, 000 cases of cancer were diagnosed from the year 2007 to 2011 with 35.8% of these patients presented at the late stages of cancer (Azizah et al. 2016).

The diagnosis of cancer threatens the physical well-being and overall quality of life of the patients (Richardson et al. 2017). In addition to psychological distress, depression also receives vast attention in the management of cancer patients (Massie 2004; Mitchell 2011). Depression is one of the most enfeebling disease of the world and has been reported to be high in prevalence among Malaysian population, especially among women (Norfazilah et al. 2015). Depression also results in a lower quality of life and reduced general well-being of cancer patients (Karakoyun-Celik et al. 2010; Smith et al. 2008). Many literatures had indicated a deficit of positive emotions in patients with depression. However, these positive emotions that comprised of discrete pleasant emotions, such as joy, pride, contentment, or love were often ignored (Ng & Hazli 2016).

We recognised demoralisation as a unique and widespread occurrence

among patients with terminal illnesses, including cancer (Vehling et al. 2017; Vodermaier et al. 2009). Demoralisation has been defined as an existential distress syndrome that consists of incapacity of coping, helplessness, hopelessness, loss of meaning and purpose, as well as impaired self-esteem. Frankl (1973) characterised demoralisation as a state of distress, occurring in patients specifically in a life-threatening situation or people facing threats to their well-being. Increasing researches on the demoralisation syndrome have advocated its diagnostic value and utility in a palliative setting (Clarke et al. 2005; Kissane et al. 2001).

In the last few years, demoralisation is an essential topic of discussion in palliative care (Robinson et al. 2015). The issue has become an important clinical matter in palliative care since there is evidence to support the claim that managing the mental health needs of these patients is a crucial part of the treatment process of cancer (Robinson et al. 2016). Many believe that the demoralisation is a precursor to severe depression and suicidality in these ill individuals (Rickelman 2002; Robinson et al. 2015; Strada 2009).

Demoralisation is frequently encountered in cancer patients, especially those in advanced staging. It is a psychological condition that is potentially treatable but often neglected by the clinicians. Generally, the clinicians are paying more attention to the illness or other negative emotion such as depression, rather than assessing the concern of demoralisation. To date, there is no data on demoralisation amongst patients with cancer in Malaysia. One of the reasons is that there are not many available measurement tools for this aspect (Kissane et al. 2004). Kissane et al. has developed the Demoralisation Scale and our group has translated the scale into the Malay language, and it demonstrated good psychometric properties (Chin et al. 2018). Hence, the objective of this study was to assess the prevalence of demoralisation using the translated demoralisation scale and examine its association with depression, distress and positive emotion among a group of cancer patients in Malaysia.

MATERIALS AND METHODS

This was a cross-sectional study involving 178 patients with cancer from the oncology and haematological ward, day-care, and follow-up clinics of University Malaya Medical Centre, Malaysia.

The sample size calculation was based on the formula purposed by Daniel (1999). Robinson et al. (2015) reported that the prevalence of demoralisation was about 13% to 18% in the patients at various stages of cancer. In this study, the prevalence rate of 13% (Mullane et al. 2009) was adopted to determine the sample size.

$$n = Z^2 P (1 - P) / d^2$$

where,

n = sample size

Z = Z statistic for a level of confidence, 1.96

P = the estimated prevalence of demoralisation

(in this case, the prevalence is 13%, i.e. 0.13)
d = precision set at 0.05.

Thus,
$n = (1.96)^2 \times (0.13)(1-0.13)/0.05^2 = 174$

The inclusion criteria for the study were (i) the subjects must be at least 18 years old and attending the follow-ups at the oncological clinic, day-care unit or wards, University Malaya Medical Centre; (ii) The diagnosis of cancer could be of any type, stage and duration; (iii) The subjects must be able to understand both the English and Malay languages; (iv) They must provide consent to partake in the study.

The exclusion criteria for the study included (i) those who have intellectual disability, dementia, acute medical condition; (ii) those are delirious; (iii) those who have acute psychosis. The eligible subjects were instructed to complete the following assessment tools.

Sociodemographic and Clinical Characteristics Questionnaire

The questionnaire collects data comprising age, gender, ethnicity, marital status, employment status, education level, types of cancer, duration of cancer since diagnosis, comorbid medical, surgical or psychiatric illness.

Malay version of Demoralisation Scale (DS-M) (Chin et al. 2018)

Kissane et al. (2004) developed the Demoralisation Scale to measure the construct of existential distress based on the demoralisation syndrome. Chin et al. (2018) translated the scale into our local language-Malay (DS-M). It was tested among a group of local participants and has demonstrated good psychometric properties. DS-M is a self-administered instrument containing 24 items. It uses a 5-point Likert scale to evaluate the frequency of the symptoms. Item 1, 6, 12, 17 and 19, have reverse scorings. The total score is calculated by summing up the score of each item. The higher score reveals a higher level of demoralisation. The cut off value of 23 was calculated based on the plot of sensitivity against the function of 1-specificity. The Cronbach's alpha for the total scale was 0.95, and the subscales ranged between 0.81-0.92. The AUC was 0.92 (SE: 0.02, $p<0.01$, 95% CI = 0.88 - 0.97).

Centre for Epidemiologic Studies Depression (CESD) Scale (Radloff 1977)

CESD is a self-reported measure to screen for the common symptoms of depression (Radloff 1977). The scores are on a four-point Likert scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). The items 4, 8, 12 and 16 are designed in such a way that their scores are to be reversed before summing up all items to produce a total score. The range of the score is from 0 to 60. A cut-off score of 16 or higher is adopted to indicate a high level of depressive symptoms. In most studies, the CES-D showed to have high internal consistency with Cronbach's coefficients ranging from

0.85-0.90 (Hunter et al. 2003; Radloff 1977).

Positive Emotion Rating Scale (PERS) (Ng & Hazli 2016)

This is a newly developed tool to measure positive emotion, especially in patients with depression (Ng & Hazli 2016). PERS has six domains, which includes interest, love, pride, contentment, active and gratification. These six domains are represented by 8 items, with the cut-off score of 30. The 5-point Likert Scale is employed to denote the frequency of the symptoms, which ranges from 1 (never) to 5 (always). The total score is obtained by summing up all of the scores from each of the items. Hence, the total score ranges from 8 to a maximum score of 40. The scale has good specificity (0.73) and sensitivity (0.75). The positive and negative predictive value are 0.60 and 0.78, respectively.

Distress Thermometer (DT) (Roth et al. 1998)

This is a visual analogue scale designed to measure the level of emotional distress in cancer patients (Roth et al. 1998). Emotional distress is otherwise considered to be extreme anxiety, sorrow or pain. DT is presented in the form of the thermometer as a step to destigmatising the reporting of emotional distress. Its scores range from 0 to 10 (no stress to extremely distress). As suggested in the original English version of DT, a score of 4 or more is adopted to represent moderate distress.

Ethical Approval

The data collection commenced only after obtaining the approval from the Medical Research Ethics Committee, University Malaya Medical Centre (UMMC) on 29th January 2017. The MREC ID number was 20161031-4462. Informed consent obtained from the subjects prior to the commencement of the study process. Information on the study background and related objectives were explained by the investigator. The patient information sheets containing information about the study, patients' right and confidentiality were provided. The researcher involved in data collection was a psychiatrist trainee, cases with significant psychological issue were referred to the psychiatric clinic for further management.

Statistical Analysis

The data collected from the study were computed and analysed using SPSS version 24.0 (IBM Corp., Armonk, NY, USA). Descriptive statistics were employed to summarise the clinical and sociodemographic characteristics of the patients. The correlations between DS-M with Distress thermometer (DT), CESD, PERS and DS (English version) were tested using Spearman's correlation analysis. The DSM scores of the subjects were categorised into high and low (using 23 as the cut-off) (Chin et al. 2018). The association between various sociodemographic and clinical factors with the DS-M was examined using the Chi-Square test. All significant factors would be further

Table 1: Sociodemographic and clinical characteristic of cancer patients (n=178)

Variables	
Mean age (SD, range)	53.6 (16.51, 18-86)
Gender, n (%)	
Male	64 (36)
Female	114 (64)
Ethnic, n (%)	
Malay	71 (39.9)
Chinese	75 (42.1)
Indian	24 (13.5)
Others	8 (4.5)
Religion, n (%)	
Muslim	73 (41.0)
Non-Muslim	105 (59.0)
Education, n (%)	
Secondary & below	86 (48.3)
Tertiary & above	92 (51.7)
Marital Status, n (%)	
Single	51 (28.7)
Married	127 (71.3)
Mean number of Children (SD, range)	1.89 (1.657, 0-7)
Occupation, n (%)	
Fulltime job	40 (31.3)
Retiree/Pensioner	55 (43)
Part-time	3 (2.3)
Unemployed	30 (23.5)
Mean income in RM (SD, range)	1832.02 (4271.74, 0-30k)
Cancer Type, n (%)	
Breast	68 (38.2)
Non-Breast	110 (61.8)
Stages of Cancer	
I-III & unknown	135 (75.8)
IV	43 (24.2)
Duration of Diagnosis	
<1 year	92 (51.7)
>1 year	86 (48.3)
Medical Illness	
Yes	65 (36.5)
No	113 (63.5)

analysed using multivariate logistic regression. All tests were two-tailed with the alpha value of 0.05.

RESULTS

Sociodemographic and Clinical Characteristics

The mean age of these subjects was 53.6 years old (sd=16.51). They were predominantly females (64%). Most of the participants were Chinese (42.1%) and Malay (39.9%). The majority of the participants were Muslims (41%). The commonest cancer that the subjects were having was breast cancer (40%).

Table 2: DS-M, CESD, PERS and DT scores among patients with cancer (n=178).

	Range	Mean	SD	N (%)
DS-M	0-64	18.79	15.30	
<23				111 (62.4)
>23				67 (37.6)
PERS	14-40	33.53	6.22	
<30				45 (25.3)
>30				133 (74.7)
CESD	0-42	11.12	9.05	
<16				132 (74.2)
>16				45 (25.3)
Distress Scale	0-8	3.07	2.01	
<4				109 (61.2)
>4				69 (38.8)

DS-M=Malay version of Demoralisation Scale; PERS=Positive Emotion Rating Scale; CESD=Centre for Epidemiologic Studies Depression Scale; SD=standard deviation; N=number

One-fourth of the subjects were having an advanced stage of disease (24.2%) (Table 1).

DS-M was categorised into high (score of 23 and above) and low (score lower than 23) level of demoralisation. The cut off level was determined in the previous study (Chin et al.). The mean of the subjects' DS-M total score was 18.79 (sd=15.30). Out of 178 subjects, 67 patients (37.6%) demonstrated a high level of demoralisation.

The mean score for CESD was 11.12 (sd=9.050). Forty-five individuals (25.3%), who scored at least 16 in CESD, were classified as depressed. (Table 2).

Correlation between DS-M, CESD, DT and PERS

Associations between DS-M, CESD, DT and PERS were examined using Spearman's correlation test. There was significant positive correlations between DS-M and CESD ($r = 0.78$, $p<0.01$) and Distress Thermometer ($r = 0.64$, $p<0.01$). PERS had recorded negative associations with DS-M (-0.69, $p<0.01$), CES-D (-0.67, $p<0.01$) and Distress Thermometer (-0.61, $p<0.01$).

Associations with Sociodemographic and Clinical Characteristics

Table 3 displayed the result of univariate analysis of the cancer patients' sociodemographic characteristics with DS-M score. There was no significant association between the dependent variables (low and high demoralisation groups) and independent variables (gender, age, ethnicity, religion, marital status, number of children, education level, unemployment and level of income).

Table 4 displayed the result of univariate analysis of the cancer

Table 3: Univariate analysis of DS-M score with sociodemographic characteristics of patients with cancer

Variables	DS-M Total Score, N (%)		Chi Square	Odds Ratio (OR)	95% CI	p value
	<23	≥23				
Sex			.086	1.10	.59-2.06	.77
Male	39 (60.9)	25 (39.1)				
Female	72 (63.2)	42 (36.8)				
Age			.12	1.12	.59-2.11	.74
≤45	37 (60.7)	24 (39.3)				
>45	74 (63.2)	43 (36.8)				
Race			2.23	.62	.33-1.16	.14
Malay	49 (69.0)	22 (31.0)				
Non-Malay	62 (57.9)	45 (42.1)				
Religion			2.97	.58	.31-1.07	.09
Muslim	51 (69.9)	22 (30.1)				
Non-Muslim	60 (57.1)	45 (42.9)				
Marital Status			.01	.98	.50-1.91	.95
Single	32 (62.7)	19 (37.3)				
Married	79 (62.2)	48 (37.8)				
Number of children			.46	1.33	.58-3.03	.50
<4	90 (61.2)	57 (38.8)				
≥4	21 (67.7)	10 (32.3)				
Education			.25	1.17	.64-2.15	.61
Secondary and below	52 (60.5)	34(39.5)				
Tertiary	59 (64.1)	33 (35.9)				
Employment Status			1.98	.626	.325-1.204	.16
Working	43 (69.4)	19 (30.6)				
Not Working	68 (58.6)	48 (41.4)				
Income (RM)			1.93	1.698	.800-3.601	.17
Low	81 (59.6)	55 (40.4)				
High	30 (71.4)	12 (28.6)				

patients' clinical characteristics with DS-M score. There was no significant association between the dependent variables (low and high demoralisation groups) and independent variables (types and stages of cancer, duration since diagnosis, latest treatment, concomitant medical and psychiatric illnesses).

Table 5 describes the univariate analysis of the total score of DS-M, CES-D, DT and PERS. Forty-one out of 178 subjects (23%) had high demoralisation (score >23) and were depressed (CES-D score >16). However, only 14.6% of those having high demoralisation was actually not depressed (CES-D score <16). A

Table 4: Univariate analysis of DS-M score with clinical characteristics of cancer patients

Variables	DS-M Total Score, N (%)		Chi Square	Odds Ratio (OR)	95% CI	p value
	<23	≥23				
Types of cancer			.02	1.04	.56-1.94	.90
Breast	42 (61.8)	26 (38.2)				
Non-breast	69 (62.7)	41 (37.3)				
Stages of cancer			.09	.90	.45-1.82	.77
I-III or unknown	85 (63.0)	50 (37.0)				
IV	26 (60.5)	17 (39.5)				
Duration since diagnosis			.04	.94	.51-1.73	.85
≤1 year	58 (63.0)	34 (37.0)				
>1 year	53 (61.6)	33 (38.4)				
Treatment			.41	1.23	.65-2.35	.52
Active treatment	71 (60.7)	46 (39.3)				
Follow-up only	40 (65.6)	21 (34.4)				
Medical illnesses			1.12	2.90	.671-12.56	.57
Yes	42 (65.6)	22 (34.4)				
No	68 (60.2)	45 (39.8)				
Psychiatric Illnesses (depression)			2.21	4.88	0.90-26.24	.14
Yes	3 (37.5)	5 (62.5)				
No	108 (63.5)	62 (36.5)				

Table 5: Univariate Analysis of the Score of DS-M with CESD, PERS and DT

Variables	DS-M Total Score, N (%)		Chi Square	Odds Ratio (OR)	95% CI	p value
	<23	≥23				
CESD			72.755	41.788	13.74-127.14	<0.001
<16	106 (80.3)	26 (19.7)				
≥16	4 (8.9)	41 (91.1)				
PERS			41.335	.091	.04-.20	<0.001
<30	10 (22.2)	35 (77.8)				
≥30	101 (75.9)	32 (24.1)				
Distress Scale			40.445	8.381	4.20-16.72	<0.001
<4	88 (80.7)	21 (19.3)				
≥4	23 (33.3)	46 (66.7)				

Abbreviation: DS-M=Malay version of Demoralisation Scale; PERS=Positive Emotion Rating Scale; CESD=Centre for Epidemiologic Studies Depression Scale; SD=standard deviation; N=number

majority, i.e. 96%, of those having a low level of demoralisation was actually not depressed (n=110). The Chi-square value was 72.76 (p-value<0.01) and its odd ratio was 41.79 (95% CI=13.74-127.14).

Of the 67 persons with high demoralisation, 52% or 35 patients were having low positive emotion. 48% of those demoralised patients were having high positive emotion (PERS score >30). A vast majority (91%) of those having low demoralisation was having high positive emotion. Only 9% of those who were less demoralised possessed low positive emotion. The Chi-square value was 41.34 (p-value<0.01) and its odd ratio was 0.91 (95% CI=0.04-0.20).

For those having a high degree of distress (DT >4), 66.7% were classified as having high demoralisation (n=46). Only 27 individuals (33.3%) were having low demoralisation. In the low-distress group, 80.7% of the individuals were identified as having low demoralisation (n=88). The Chi-square was 40.45 (p-value<0.001) and its odd ratio was 8.38 (95% CI=4.20-16.72).

CESD, PERS and Distress scores were included in multiple logistic regression analysis. The result was shown in Table 6. For CESD, the adjusted odd ratio was 3.13, with a p-value of <0.01, and for DT, the adjusted odd ratio was 1.29 (p-value<0.05). However, analysis of PERS showed insignificant result (p-value>0.05) (Table 6).

The model summary had indicated that 40.8% of the variation in the dependent variable is explained by the logistic model (Cox-and-Snell R2=0.41). Nagelkerke R2 value of 0.56 revealed a strong relationship between the predictors and prediction (DS-M).

DISCUSSION

In the current study, the mean score of DS-M for cancer patients was 18.79 (SD=15.30). The result was lower than the findings in previous studies from different regions. Mullane et al. (2009) recruited 100 advanced cancer patients and reported a mean DS score of 19.94 (SD=14.62). Higher mean DS scores were recorded in the Italian and German demoralisation studies. Their scores were 23.90 (SD=14.50) (Costantini et al. 2013) and 29.8 (SD=10.41) (Mehnert et al. 2011), respectively. In the study by the author of demoralisation scale in Australia, the mean score was recorded as high as 43.1 (SD=23.20) (Kissane et al. 2004). The differences in the mean score were explained by the cultural differences among the different countries and the unique ethnic responses to chronic

Table 6: Multivariate analysis of CESD, PERS and DT with DS-M

Scales	**Standard Error (SE)**	Odd Ratio (OR)	p Value
CESD	0.60	3.13	<0.01
PERS	0.56	-0.93	0.10
DT	0.46	1.29	<0.01

Abbreviation: CESD=Centre for Epidemiologic Studies Depression Scale; PERS=Positive Emotion Rating Scale; DT: Distress Thermometer

illnesses.

Approximately 37.6% of cancer patients in this study were found to have a high demoralisation. This finding was consistent with the results of other studies. A German study reported demoralisation rate of 39.1% in 516 cancer patients (Mehnert et al. 2011). Higher demoralisation prevalence was found in the studies in Mainland China and Taiwan. Deng et al. (2017) and Lee et al. (2012) reported 46.9% and 49% of the patients with cancer were demoralisation, respectively. In the Australian study conducted by the author of the demoralisation scale, 47 out of 100 palliative patients were reported to have high demoralisation (Kissane et al. 2004). It is noteworthy to mention that the cut off values used in different studies was varied. Most studies used mean score as the cut off value; however, Kissane et al. (2004) defined high demoralisation as the score higher than the median value (i.e. 30) in his study.

Depression and demoralisation are regarded as two distinct ontologies (Kissane 2004; Robinson et al. 2016). Twenty-six out of a total of 178 subjects (14.8%) in the current study were identified to achieve a higher score in the DS but were not clinically depressed. Kissane et al. (2004), who attempted to distinguish the demoralisation syndrome from depression, reported that 7-14% of the cancer patients were demoralised but not clinically depressed. He believed such a cohort of patients should be considered differently. A similar observation was found in several other studies (Costantini et al. 2013; Hung et al. 2010; Mehnert et al. 2011; Mullane et al. 2009). Mehnert et al. (2011) showed that about 5-20% of the subjects with advanced cancer were severely demoralised but were not clinically depressed. Costantini et al. (2013) demonstrated that 6-20% of the patients were seriously demoralised but not clinically depressed. Also, 16-31% of the study's patients had moderate levels of demoralisation but no clinical depression. In a study conducted by Juliao et al. (2016) investigations on demoralisation syndrome among patients with advanced illness and found that close to half of the study patients were demoralised. However, the authors concluded that they could not determine if the demoralisation state and depression were two distinct psychological entities.

Interestingly, Rudilla et al. (2016), who investigated the scale demonstrated that the subjects with higher scores of the demoralisation measurements showed higher levels of anxiety. At the same time, those with higher levels of depression had higher scores on the components of loss of meaning, disheartenment, and sense of failure. In a study by Rudilla et al. (2016), it demonstrated that the demoralised palliative patients tended to be depressed. A recent systematic review study indicated depression was significantly correlated with higher demoralisation level in patients with cancers (OR=9.65, 95% CI 6.99-13.33, Z=15.00, $p<0.01$) (Tang et al. 2015). However, demoralisation is often unrecognised in the ordinary medical treatment for cancer and this can be a risk factor for developing depression

at a later stage (Jacobsen et al. 2006). These findings demonstrated that there was a need to distinguish the group of patients with increased demoralisation but did not meet the DSM-IV's diagnosis of major depression in cancer patients (Kissane 2004). No relationship was found between demoralisation and the sociodemographic factors in this study. Inconsistent results were reported on the relationship between age, gender and educational level. Some studies showed no association between age and demoralisation (Katz et al. 2001). While one study had mentioned that this psychological state was directly related to age (Vehling et al. 2011), i.e. higher demoralisation was found in older age, a few other researchers had also discovered that a higher level of demoralisation was found in the younger age group (Mehnert et al. 2011; Vehling et al. 2013). Likewise, gender (Grassi et al. 2005; Lee et al. 2012) and educational status (Lee et al. 2012) were shown to be unrelated to demoralisation.

The report on the relationship between demoralisation with religion and income were mixed, as the present evidence was too scarce to draw any conclusion. The present study had suggested that income and religion were unrelated to the demoralisation state. Despite this, Lee et al. (2012) had found that higher demoralisation was present in the group with lower income. However, no relation between demoralisation and religion was seen in that study. The current study had reported that there was no clear relation between demoralisation and marital status. This finding was supported by one study conducted in Taiwan (Lee et al. 2012). Other studies had reported the opposite results in which demoralisation was higher in single patients who did not have any partner (Katz et al. 2001; Mehnert et al. 2011). The relationship between employment and demoralisation was reported in two studies (Katz et al. 2001; Lee et al. 2012). The evidence revealed that those patients who were employed in either full time or part-time jobs were less likely to be demoralised. In contrast, the current study had found no evidence for such a relationship.

The current study did not show any significant association between the DS total score with clinical characteristics. These findings were consistent with the systemic review conducted by Robinson et al. (2015). It is well known that the stage of disease and time since diagnosis are directly related to cancer and its associated psychosocial consequences (Caruso et al. 2017; Grassi 2005). Theoretically, the patients with advanced cancer who suffer significantly from the metastasis and its treatment complications are deemed to experience a higher level of existential distress (Vehling et al. 2012), social isolation due to physical limitation (Kroenke et al. 2017) and thus, demoralisation (Vehling et al. 2012). Similarly, shorter time since diagnosis implies a period of adjusting and coping with the cancer diagnosis as well as an active phase of oncology treatment. Interestingly, our finding is in accordance with the work of Robinson et al. (2015) who reported that the stage of cancer, duration

since diagnosis and type of treatment were not specifically related with the level of demoralisation. The possible explanation for this finding is that the cancer diagnosis is a widely organised existential threat to the patients, irrespective of the stage and treatment.

It is undoubtedly true, patients with cancer experienced significant distress since the onset of symptoms till the diagnosis and treatment period. Although demoralisation always occurs during a stressful situation, but not all stressful situations are associated with demoralisation. Those with higher resilience (ability to mentally or emotionally cope with crisis) are better able to sail through these periods without long-term negative psychological consequences. Increasing a person resources to cope with crisis promotes resilience. Self-help approaches such as mindfulness and other more structured psychological therapies such as cognitive behavioural therapy (CBT) can help to build resilience resulting in better coping in patients with cancer.

This study is the first of its kind that looked into demoralisation among cancer patients in Malaysia. It also looked into the association between demoralisation with positive emotion and psychological distress. All measurement tools used in this study are validated tools. The established preliminary findings in this study may create a path in planning a future advanced study that may benefit the cancer patients.

There are several limitations in the current study. Non-random sampling method used in this study might contribute to the risk of selection bias. Subjectivity in the selection process makes it difficult to measure changes across places and time. Additionally, the sampling was limited to a single centre where patients may be characteristically different from other parts of Malaysia. Fatigability and crowded environment might also contribute to response bias in the present study.

Last but not least, many other confounders in examining demoralisation were not measured due to the constraint of various resources. The confounders that were likely to affect the measurement included perceived social support, premorbid personality, coping skills, and life events. This study involved subjects with cancer only, and this limits the generalisability of the study's findings to the other fields of medicine.

CONCLUSION

The existence of demoralisation faced by patients with cancer has received increasing interest in research. The high prevalence of demoralisation in the local cancer population is indeed an alarming sign to the oncology team and mental health workers. Identifying the subset of patients with high demoralisation who are not clinically depressed, is very important. Early recognition and timely intervention of the demoralisation syndrome is crucial, as this may impede the development of various consequences, e.g. depression and suicide. An appropriate biopsychosocial approach should be attempted when individuals

with cancer are identified to be demoralised. Careful management of the condition has the potential to ultimately increase the quality of life of the individuals with a terminal illness.

ACKNOWLEDGMENT

The authors appreciate and acknowledge the staffs from the oncology and haematological ward, day-care, and follow-up clinics of University Malaya Medical Centre for their assistance in the study.

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Received: 09 Oct 2020
Accepted: 18 Dec 2020