DEMORALISATION AND ITS ASSOCIATED FACTORS AMONG CANCER PATIENTS IN A UNIVERSITY HOSPITAL

DR. CHIN HAN LIM

FACULTY OF MEDICINE
UNIVERSITY OF MALAYA
KUALA LUMPUR

2018

DEMORALISATION AND ITS ASSOCIATED FACTORS AMONG CANCER PATIENTS IN A UNIVERSITY HOSPITAL

DR. CHIN HAN LIM
(MGC 140003)

Dissertation submitted in partial fulfilment of the requirement
for the degree of

MASTER OF PSYCHOLOGICAL MEDICINE

Department of Psychological Medicine
Faculty of Medicine
University of Malaya
Kuala Lumpur
Malaysia

May 2018

CERTIFICATION

This is to certify that the candidate,

DR. CHIN HAN LIM,

had carried out this dissertation project.

To the best of my knowledge,

this dissertation is entirely his own work.

……

ASSOCIATE PROF. DR. AILI HANIM BINTI HASHIM

Advanced Training Child & Adolescent Psychiatry,

MONASH UNIVERSITY, AUSTRALIA

Master of Psychological Medicine (UM)

MBBS, UNIVERSITY OF MALAYA (UM)

Consultant of Psychiatry

Department of Psychological Medicine,

University of Malaya

……

ASSOCIATE PROF. DR. NG CHONG GUAN

Master of Science in Clinical Epidemiology (Utrecht)

PhD Fellowship in Clinical Epidemiology (Utrecht)

Master of Psychological Medicine (UM)

MBBS, UNIVERSITY OF MALAYA (UM)

Consultant of Psychiatry

Department of Psychological Medicine,

University of Malaya

ABSTRACT

Demoralisation and Its Associated Factors among Cancer Patients in A University Hospital

Objective: To date, there is no literature on demoralisation in Malaysian patients with cancer. The primary objective of this study was to examine the relationship between demoralisation with positive emotion, depression, distress, sociodemographic, disease and treatment-related factors. The Demoralisation Scale had also been translated and validated into Malay language for the use of the Malaysian patients.

Method: This was a cross-sectional study conducted in Universiti Malaya Medical Centre (UMMC), Kuala Lumpur, Malaysia with the approval from the Medical Ethics Committee was obtained. One hundred and seventy-eight subjects were recruited from the oncology and haematological ward, day-care clinics and follow-up clinics from January to December 2017 based on the inclusion and exclusion criteria. The convenient sampling method was employed. After obtaining the informed consent from the subjects, the sociodemographic and clinical data of the subjects were collected. The subjects filled both English and Malay versions of the Demoralisation Scales, Centre for Epidemiologic Studies Depression (CESD) Scale and Distress Thermometer. SPSS v24.0 was used as a method for statistical analysis. Descriptive analysis, Spearman's correlation, chi-square test and multiple logistic regression were used to examine demoralisation and its associated factors. Principal component factor analysis, internal consistency test, intra-class correlation and receiver operating characteristic curve were used for the validation of DS-M.

Results: The mean age of the subjects was 53.6± 16.51 years old (range 18-86). Sixty-four percent of the patients were female. In terms of race, most of the subjects were Chinese (42.1%), followed by Malays (39.9%) and others (18%). The commonest religion was Islam (41%), followed by Buddhism (27.5%) and Christianity (15.2%). About two fifths of the subjects had breast cancer, and twenty-four percent of the subjects were at the advanced stage of various cancer.

The mean score for the Malay version of the Demoralisation Scale (DS-M) was 18.79 $\pm$ 15.30. 37.6% of the cancer patients were demoralised based on DS-M score $\geq$23. In the group with high demoralisation, 61.2% were depressed (x^2=72.76, p<0.01), 52.2% had low positive emotion (x^2=41.34, p<0.01) and 68.7% were distressed (x^2=40.45, p<0.01).

On the other hand, in the group with low demoralisation, 95.5% were not depressed (x^2=72.76, p<0.01), 91% had high positive emotion (x^2=41.34, p<0.01) and 79.3% were not distressed (x^2=40.45, p<0.01). Demoralisation was correlated positively with depression (r=.78, p<.01) and distress level (r=.64, p<0.01). Inverse relationship was found between demoralisation and positive emotion (r=-.69, p<.01). No significant association was found between demoralisation with sex ((x^2=.09, p=.77), age (x^2=.12, p=.74), race (x^2=2.23, p=.14), religion (x^2=2.97, p=.09), marital status (x^2=.01, p=.95), employment status (x^2=1.98, p=.16) and income ($x^{2=}$1.93, p=.17). The association between demoralisation and the type of cancer (x^2=.02, p=.90), stage of cancer (x^2=.09, p=.77), duration since diagnosis (x^2=.04, p=.85), mode of treatment (x^2=.41, p=.52), medical illness (x^2=1.12, p=.57) and psychiatric illness (x^2=2.21, p=.14) were not significant as well.

The principal component analysis of DS-M yielded four-factor structures. The Cronbach's alpha for the total scale was .95, and the subscales ranged between 0.81-0.92. The Spearman's correlation showed a good convergent validity between DS-M and Distress Thermometer (r=.64, p<0.05) and divergent validity between DS-M and PERS (r=-.69,

p<.01). The AUC was 0.92 (SE: 0.02, p < 0.01, 95% CI 0.88-0.97). The optimal sensitivity and specificity for the DS-M were shown by the cut-off score of 23.

Conclusion: Demoralisation was highly prevalent in Malaysian cancer patients. Depression and distress were significantly related to demoralisation. The lower level of positive emotion was found in the patient suffering high demoralisation and vice versa. The state of demoralisation among the cancer patients should receive more attention from the oncology and mental health teams. The validated Malay version of the demoralisation scale can be used on the Malaysians to screen for demoralisation and institute early intervention.

Keywords: Demoralisation, depression, positive emotion, distress, Demoralisation Scale, Malay version

ABSTRAK

Dimoralisasi dan Faktor-faktor Berkaitan di Kalangan Pesakit Kanser di Sebuah Hospital Universiti

Objectif: Kajian ini menguji tahap dimoralisasi di kalangan populasi pesakit cancer di Malaysia. Artikel ini juga membincangkan hubungan antara dimoralisasi, emosi positif, stress, faktor-faktor sociodemografi dan klinikal. Pada masa yang sama, Skala Dimoralisasi juga diterjemahkan di dalam Bahasa Malaysia untuk kegunaan penduduk tempatan.

Kaedah: Ini adalah satu kajian keratan rentas yang dijalankan di Pusat Perubatan Universiti Malaya (UMMC), Petaling Jaya, Malaysia. Pelepasan daripada Jawatankuasa Etika Perubatan telah diperolehi. Sejumlah seratus tujuh puluh lapan subjek kajian telah direkrut dari wad onkologi, klinik rawatan harian dan klinik susulan dari Januari ke Disember 2017 berdasarkan kriteria kemasukan dan pengecualian. Pensampelan mudah (*convenient sampling*) telah digunakan. Setelah mendapatkan keizinan termaklum, subjek-subjek yang direkruit diberikan Skala Dimoralisasi versi Bahasa Inggeris dan Malaysia, *Centre for Epidemiological Studies Depression* (CESD) *Scale*, *Distress Thermometer* (DT) dan soal selidik berkenaan dengan profil sosiodemografik dan klinikal. SPSS v24.0 telah digunakan untuk analisis statistik. Analisis deskriptif, *Spearman's correlation*, ujian *chi square* dan regresi logistik berganda digunakan untuk menguji dimoralisasi dan faktor-faktor yang berkaitan dengannya. Analisis faktor komponen utama, ujian konsistensi dalaman, korelasi intra-kelas dan kurva ciri operasi penerima (ROC) telah digunakan untuk tujuan validasi DS-M.

Keputusan: Umur purata subjek-subjek ini adalah 53.6 tahun (SD=16.51; lingkungan=18-86). Kebanyakan pesakit ini adalah kaum perempuan (68%). Etnik Cina adalah kumpulan terbesar (42.1%) diikuti oleh kaum Melayu (39.9%) and others (18%). Agama yang paling umum adalah agama Islam (41%) dan diiukuti oleh agama Buddha (27.5%) dan Kristian (15.2%). Agak-agak 40% daripada subjek ini menghidapi kanser payudara berbagai tahap. Kebanyakan pesakit ini berada dalam tahap advan (24.2%). Skor purata untuk DS-M adalah 18.79 $\pm$ 15.30. 37.6% pesakit mempunyai tahap dimoralisasi yang tinggi (Skor DS-M $\geq$23). Dalam kumpulan yang mempunyai dimoralisasi tinggi, 61.2% ada kemurungan (x^2=72.76, p<0.01), 52.2% ada emosi positif yang rendah (x^2=41.34, p<0.01) dan 68.7% ada distres (x^2=40.45, p<0.01). Sebaliknya, dalam kumpulan yang mempunyai dimoralisasi rendah, 95.5% tidak murung, 91% ada emosi positif yang tinggi dan 79.3% tidak distres. Tahap dimoralisasi berkorelasi positif dengan kemurugan dan distres. Hubungan songsang telah ditemui antara dimotalisasi dan emosi positif. Dimoralisasi mempunyai kaitan yang positif dengan kemurungan (r=.78, p<.01) dan stress (r=.64, p<.01). Hubungan songsang antara dimoralisasi dan emosi positif telah ditemui (r=-.69, p<.01). Tiada kaitan yang ketara ditemui di antara dimoralisasi dengan jantina (x^2=.09, p=.77), umur (x^2=.12, p=.74), bangsa (x^2=2.23, p=.14), agama (x^2=2.97, p=.09), status perkhawinan (x^2=.01, p=.95), status pekerjaan (x^2=1.98, p=.16) dan pendapatan ($x^{2=}$1.93, p=.17). Hubungan di antara dimoralisasi dengan jenis kanser (x^2=.02, p=.90), tahap kanser (x^2=.087, p=.77), tempoh sejak diagnosis (x^2=.038, p=.846), cara rawatan (x^2=.41, p=.52), penyakit medical (x^2=1.12, p=.57) dan penyakit psikiatri (x^2=2.21, p=.14) adalah tidak ketara juga.

Analisis komponen utama DS-M telah menghasilkan 4 stuktur factor. *Cronbach's alpha* untuk skala keseluruhan adalah .95 dan untuk 4 faktor adalah dalam lingkungan .81-.92. *Spearman's correlation* telah menunjukkan *convergent validity* yang bagus di antara DS-M

and Distress Thermometer (r=.64, p<.01). *Divergent validity* di antara DS-M dan PERS adalah bagus juga (r=-.69, p<.01).AUC untuk DS-M adalah 0.92 (SE: 0.02, p < 0.01, 95% CI 0.88-0.97). Skor potong 23 telah dipilih berdasarkan plot sensitiviti dengan 1-spesifisiti.

Kesimpulan: Kelaziman dimoralisasi adalah sangat tinggi di kalangan pesakit kanser Malaysia. Hubungan positif telah ditemui di antara dimoralisasi dan kemurungan dan distress. Kaitan songsang telah dijumpai di antara dimoralisasi dan emosi positif. Femomena dimoralisasi sepatutnya mendapat perhatian yang secukupnya daripada pasukan onkologi dan psikiatri. Dengan menggunakan Skala Dimoralisasi yang *reliable* dan sah (*valid*), dimoralisasi sepatutnya disaring di kalangan pesakit ini supaya intervensi psikoterapeutik yang sewajarnya boleh dipraktikkan tepat pada masa.

Kata-kata kunci: Dimoralisasi, kemurungan, emosi positif, cancer, Skala Dimoralisasi, versi Bahasa Melaysia

ACKNOWLEDGEMENT

First and foremost, I would like to express my utmost gratitude toward the extraordinary support from Associate Professor Dr. Aili Hanim bin Hashim in the making of this dissertation. The beneficial critique and cordial encouragement had propelled me further whenever I felt lost on my journey of completing the project. Without her advice and assistance, I would not have kept my progress on schedule. It was always a pleasure coming to work every day with such lovely and engaging person. Her constructive suggestions were very much appreciated and could not ever be forgotten.

Besides, I would also like to take this opportunity to thank my outstanding and Associate Professor Dr. Ng Chong Guan whose vision steered this study from the very first day. His expert advice, guidance and professional insights had motivated me to take up more challenges along the way in accomplishing the dissertation project. He had spent a lot of his personal time out of office hours to mentor and meet with me—most people wouldn't—but his passion and practice had left an impact on me that will never wear out.

Other than these two esteemed researchers in the field of psychological medicine, Dr. Fatihah Addawiah binti Mohamed also provided me much valuable opinions in doing the dissertation. She shared with me her own experience in doing the project and offered me her personal notes for my reference. Special thanks should be given to her for her selfless assistance and enthusiastic guidance on this project.

I would like to express my deep gratitude to my astoundingly supportive family members. I would not have completed my dissertation project without the support from any of them. 'Home is where the heart is', said McCloskey in 1870. It was so touching when I realised my parents had waited for me at home and prepared supper for me even late at night.

Finally, I would like to extend my gratitude and thank to my ex-colleagues and friends for their wonderful collaboration. They stood by me all the time and were willing to lend me a hand whenever I was in need. For those who touched my life in any way since I started this project, you all know who you are, and I am truly grateful for all you have done.

LIST OF CONTENTS

LIST OF TABLES AND FIGURE

LIST OF APPENDICES

LIST OF ABBREVIATIONS

APA	American Psychiatric Association
AUC	Area Under the Curve
CA	Cancer
CES-D	Centre for Epidemiologic Studies Depression Scale
CI	Confidence Interval
DS	Demoralisation Scale, English version
DS-M	Malay version of Demoralisation Scale
DSM 5	Diagnostic and Statistical Manual, 5th Edition
DT	Distress Thermometer
Exp (B)	Exponentiation of B coefficient
ICC	Intra-class correlation
n	Number
NPV	Negative Predictive Value
M.I.N.I.	Mini International Neuropsychiatric Interview
MREC	Medical and Research Ethic Committee
PCA	Principal Component Analysis
PERS	Positive Emotion Rating Scale
P.J.	Petaling Jaya
PPUM	Pusat Perubatan University Malaya
PPV	Positive Predictive Value
ROC	Receiver Operating Characteristic
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences
UMMC	University of Malaya Medical Centre
WHO	World Health Organisation
YLD	Years Lived with Disability

CHAPTER 1: INTRODUCTION

The prevalence of cancer has increased exponentially globally including the developing countries in the last few years (Jemal et al., 2011; White et al., 2014; World Health Organization, 2008, 2015). In 2011, the World Health Organization (2011) estimated that more people die from cancer than coronary heart disease or stroke. It was reported that there were 8.2 million deaths due to cancer worldwide in 2012 (Ferlay et al., 2015; International Agency for Research on Cancer, WHO, 2012). The International Agency for Research on Cancer (2013) reported that almost thirty-three million people had been diagnosed to suffer from cancer in the past 5 years. Out of this number, about 12% of the new cases (1.7 million) and 14% of cancer deaths (1.2 million) occurred in the South-East Asia region in the same year.

Although improvements in cancer treatments and management of several adverse effects have been reported, the presence of cancer is still associated with many other adverse events, such as death and trauma (Adler, Page, & Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting, 2008). For many patients, their caregivers, and loved ones, having cancer is an overwhelmingly difficult experience (L. Grassi & Nanni, 2016; Zhang, Xiao, & Chen, 2017). Cancer patients are at risk of having high rates of psychological disorders (Adler et al., 2008; Pastore et al., 2017; Sisolefsky, Rana, Herzberg, Gellrich, & Rana, 2017). Not surprisingly, these patients have negative self-perceptions and an undesirable view of the illness especially when their diseases progress with a concomitant deterioration of mental health (Adler et al., 2008). These difficult situations (negative self-perception and undesirable view of the illness) may adversely affect the patients' abilities to cope with their illness (Adler et al., 2008).

Psychiatrists have recognised demoralisation as an unique and widespread occurrence among patients with terminal illnesses including cancer (Vehling et al., 2017; Vodermaier, Linden, & Siu, 2009). 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 in palliative patients has advocated its diagnostic value and utility in palliative setting (D.M. Clarke, Kissane, Trauer, & Smith, 2005; D.W. Kissane, Clarke, & Street, 2001).

In Malaysia, there is also an increasing number of people with cancer (Azizah, Nor Saleha, Noor Hashimah, Asmah, & Mastulu, 2016; Hisham & Yip, 2004; Yip, Taib, & Mohamed, 2006). Accordingly, the health system has responded by the setting up oncology services in the major hospitals within the country (Azizah et al., 2016). Yip, Bhoo Pathy, and Teo (2014) reported that there were reduced survival rates among Malaysian women with breast cancer. The Malaysian National Cancer Registry Report showed that 35.8% of patients presented at the late stages of cancer (Azizah et al., 2016). Hisham and Yip (2004) reported that the factors such as the practice of traditional medicine, negative perception of the disease, destitution and low education and fear contributed to the delay in presentation.

With the advances in knowledge and research in psycho-oncology, many clinicians working in the field of psycho-oncology are aware of the presence of psychological distress among cancer patients (C.G. Ng et al., 2017; Sharif, 2017; N.Z. Zainal, Koh, & Bustam, 2012). The distress affects the individuals' perception of their illness (Arran, Craufurd, & Simpson, 2014; Hopman & Rijken, 2015) and the way they cope (Arran et al., 2014; Richardson, Schuz, Sanderson, Scott, & Schuz, 2017). Many cancer patients face a variety of reminders about their impending death from the time of their diagnosis (Richardson et al.,

2017). Many individuals are unwilling to think about their diagnosis. Subsequently, this contributes to the illness progression and delay in receiving treatment.

In the last few years, demoralisation is an important topic of discussion in palliative care (Robinson, Kissane, Brooker, & Burney, 2015). The issue has become increasingly organised in palliative care as a substantial clinical matter requiring assessment and intervention. There is evidence to support the claim that managing the mental health needs of these patients is a crucial part of the treatment process, and even influence the prognosis (Robinson, Kissane, Brooker, & Burney, 2016). Many believe that the presence of demoralisation is a precursor to severe depression and suicidality in these very ill individuals (Rickelman, 2002; Robinson et al., 2015; Strada, 2009).

Accordingly, the goals in all oncology units are to assure the highest possible quality of life for patients with advanced diseases (Wakefield et al., 2017). Thus, the availability of a psychometric measure of demoralisation is indispensable for the accurate diagnosis of the condition and information regarding interventions. D.W. Kissane, Wein, Love, and Lee (2004) developed the Demoralisation Scale, a validated measure of demoralisation. Subsequently, many authors have translated the scale into several languages for the use of the people across the different cultures, languages and nations (Hung et al., 2010; Mullane, Dooley, Tiernan, & Bates, 2009; Rudilla, Galiana, Oliver, & Barreto, 2016). The psychometric properties of these translated versions varied depending on the variability of study populations and characteristics (Robinson et al., 2015). Hence, a Malay translated version of the Demoralisation Scale is important to address the needs of Malaysians.

CHAPTER 2: LITERATURE REVIEW

2.1 Cancer and Its Worldwide Burden

In developed and developing countries, cancer has become a significant public health problem (Bray, Shield, & i-Han, 2008; World Health Organization, 2011). The occurrence of cancer and its outcome has worldwide consequences (Jemal et al., 2011; White et al., 2014; World Health Organization, 2008, 2015). In 2011, The World Health Organization (2011) estimated that more people die from cancer than coronary heart disease or stroke. The International Agency for Research on Cancer, WHO (2012), reported that an estimated 14.1 million new cancer cases are detected each year.

Cancer is the leading cause of death in developed countries and the second leading cause of death in many developing countries (Popat, McQueen, & Feeley, 2013; Torre et al., 2015; Torre, Siegel, Ward, & Jemal, 2016). However, this is an ongoing problem. The number of cases and deaths from cancer is expected to propagate rapidly as the world populations rise, with increasing age of survival, and the lifestyle behaviours related to the increasing risk of cancer (Torre et al., 2016).

The trend is worrying especially in low- and middle-income countries, as the burden of cancer patients stretches the country's economy (Institute of Medicine (US) Committee on Cancer Control, 2007; International Agency for Research on Cancer, 2013). International Agency for Research on Cancer (2013) reported more than half of all cancers (56.8%) and cancer deaths (64.9%) in 2012 occurred in less developed regions of the world. The committee further stated the proportions would increase further by the year 2025.

The upsurge in the number of people affected and the burden of care will remain, as the tobacco-induced cancer rises (Institute of Medicine (US) Committee on Cancer Control,

2007). The increasing world aging population is another relevant factor (Institute of Medicine (US) Committee on Cancer Control, 2007; Wingo et al., 2003). The Institute of Medicine (US) Committee on Cancer Control (2007) specified many of these "premature" deaths from cancer could be prevented if the main risk elements of cancer could be improved.

Although cancer is often considered an age-related disease, the reality is that it affects people of all ages and all levels of the society (Jo¨nsson, Hofmarcher, Lindgren, & Wilking, 2016). The incidence of most cancers increases with age, and the rise occurs more rapidly beginning in midlife (Jo¨nsson et al., 2016; U.S. Cancer Statistics Working Group, 2013; White et al., 2014). The increasing incidence of cancer increases the expenditures for diagnostics and treatment while the mortality in patients in working age leads to production loss (Jo¨nsson et al., 2016).

The incidence and survival rate are affected by the cancer type, sex, and age group, and malignant cases (Miller et al., 2016). Overall, the male population has a higher incidence rate of cancer, which is nearly 25% higher compared to that of the female counterparts, with the rates of 205 and 165 per 100, 000, respectively (Miller et al., 2016). A prospective observational study examining sixty-five thousand postmenopausal subjects for a mean follow-up of 12.6 years indicated that healthy lifestyle behaviours were associated with lower risk (17%) of any cancer [HR, 0.83; 95% confidence interval (CI), 0.75–0.92] and both for the all-cause and cancer-specific mortality (Thomson, McCullough, & Wertheim, 2014).

In Malaysia, the problem of cancer is worrying. According to Malaysian National Cancer Registry Report, more than hundred thousand of patients were diagnosed to have cancer from year 2007 to 2011 (Azizah et al., 2016) with malignant neoplasm being the top five leading cause of death (2.2%) in the country (Department of Statistics Malaysia, 2017). Azizah et al. (2016) predicted that the occurrence will increase due to the rise of the aging

population. The incidence is higher among males (Penang Cancer Registry, 2010); and among the malignancies, lung cancer is the most common killer. It is a worrying to know that the prevalence of smoking among primary school children in the country is on an upward trend (Asma et al., 2015; Institute for Public Health (IPH), 2012, 2015).

The knowledge regarding the incidence of cancer is a fundamental requirement of any country's planning and monitoring of cancer control programs. A substantial proportion of the cancer cases was preventable by applying the pre-existing cancer control or preventive methods (Anand et al., 2008; Jemal et al., 2011; World Health Organisation, 2007). Many leading cancer organisations have been recommending various cancer prevention strategies such as tobacco cessation, moderate alcohol consumption, regular physical activity and optimal body weight (American Cancer Society, 2012; American Institute for Cancer Research, 2012). Most indicate early diagnosis is essential for optimizing treatment and slowing its progression.

Accordingly, the number of cancer survivors may increase in the future (Chen et al., 2016; Miller et al., 2016). The increasing incidence of cancer will affect the countries health services as well, as this group of individuals require appropriate resources. Policy makers and clinicians should work collaboratively to promote such awareness and knowledge globally.

2.2 Cancer and Psychological Distress

it is undeniable that the diagnosis of cancer threatens the physical well-being and overall quality of life (Hamer, Chida, & Molloy, 2009; Richardson et al., 2017). It is common to see cancer patients having psychological distress (Pastore et al., 2017; Sisolefsky et al., 2017). Often the distress goes unorganised by the oncology doctors (P. B. Jacobsen et al.,

2005). Psychological distress has been associated with a higher risk of cancer (Chida, Hamer, Wardle, & Steptoe, 2008; Hamer et al., 2009) and poorer survival (Hamer et al., 2009; Zhang et al., 2017).

The psychological distress affects the presentation of the illness (Hagger & Orbell, 2003; Hopman & Rijken, 2015) and the coping behaviours (Richardson et al., 2017). Being mentally healthy influences an individual's adherence to the treatment and their health seeking behaviours (Hagger & Orbell, 2003; Zhang et al., 2017). These behaviours include the person's motivation and intention to attend the health care appointments and to adopt behaviours that will improve their health (Hagger & Orbell, 2003; Zhang et al., 2017).

Clinicians are often worried that the distress will negatively weaken the cancer patients' immune defence system, adversely influence their adherence to therapy, and potentially interfere with cancer treatment (Chida, Hamer, & Molloy, 2009; P. B. Jacobsen et al., 2005; Korte, Bohlmeijer, & Smit, 2009). The presence of psychological distress is even more visible in elderly patients (Korte et al., 2009). The presence of depression and anxiety in older adults significantly carries a poor prognosis (Korte et al., 2009).

2.3 Depression in Cancer Sufferers

Five types of mental disorders have been ranked among the top twenty causes of Global Burden of Disease (GBD) (Vos, 2015). The Major depressive disorder has become the second leading cause of years lived with disability (YLDs) (Vos, 2015). In Malaysia, depressive disorder has ranked the fourth health issue causing most disability in year 2016 (Institute for Health Matrics and Evaluation, 2016).

Depression is a psychiatric syndrome that receives the most attention from the

clinicians in the patients diagnosed with various types of cancer (Massie, 2004; Mitchell et al., 2011). A diagnosis of cancer is considered a very significant life event which can contribute to the development of depression. The rates of major depression among the palliative patients have been found to vary from 22% to 75% (EPEC, 2000; Irwin & Ferris, 2008; Taylor & Ashelford, 2008; N. Z. Zainal, Nik-Jaafar, Baharudin, Sabki, & Ng, 2013). A review paper written by C. G. Ng and Zainal (2014) indicated there was a huge variation in the prevalence of depression in cancer patients across the world. The Asian studies reported the lowest prevalence of depression (3-39%) whereas the highest prevalence was found in European studies (7-79%). The studies showing the presence of depression depended on the patient population studied, different study methods, instruments, and procedures used (Pasquini & Biondi, 2007).

Notwithstanding the years of research, the exact prevalence of depression in the palliative population remains unclear and is much debatable (Massie, 2004). One of the attributive causes is that most of the research publications have employed the screening test instead of a diagnostic measure to detect depressive symptoms (Mitchell, Meader, & Symonds, 2010). On the other hand, a more recent meta-analysis of all the types of depression combined concluded that the prevalence was almost 25% (Krebber, Buffart, & Riepma, 2014). Significant distress was found to be even higher and was estimated to range from 20% to 50% of those patients (Derogatis & Morrow, 1983; Jorgensen, Laursen, Garne, Sherman, & Sogaard, 2016; C.G. Ng et al., 2017). Various self-reported screening tools such as the Hospital Anxiety and Depression Scale (HADS) and CESD had demonstrated excellent psychometric properties and were appropriate to be used for screening for psychological distress in patients with cancer (Vodermaier et al., 2009).

Clinicians often receive conflicting information regarding depression in the sufferers

of advanced diseases (Pasquini & Biondi, 2007). Some experts have the opinion that depression is under-diagnosed in this group of patients as the state of emotion can be erroneously attributed to the normative reaction in response to the advanced medical conditions (A. F. Gross, Smith, & Stern, 2007; Pasquini & Biondi, 2007; Strada, 2009). The presence of mood changes is a challenge to study in patients with cancer, as a range of symptoms which present itself and these are often dissimilar in different patients (Jadoon, Munir, Shahzad, & Choudhry, 2010). Indeed, many somatic complaints may also be part of the presentations of the underlying psychological distress (D. M. Clarke, Piterman, Byrne, & Austin, 2008; Leuchter et al., 2009; Trivedi, 2004).

On the other hand, there are some opinions that depression may be over-diagnosed due to the same reasons mentioned above (Hickie, 2007; Saracino, Rosenfeld, & Nelson, 2016). It is arguable that the overlapping of the somatic manifestation of depression and the physical presentation of the concomitant medical disorder may create some confusions and frequently make the diagnosis more challenging (Angelino & Treisman, 2001; Bailey et al., 2005; Jadoon et al., 2010; C. G. Ng, 2016; N. Z. Zainal et al., 2013).

It is widely recognised that the medical illness does not only negatively influence the psychological well-being but also adversely affect the medical outcome (Hamer et al., 2009; Korte et al., 2009). As an effort to facilitate the diagnosis of depression in patients with advanced illness and formulate timely psychotherapeutic intervention, the Endicott Criteria was proposed (Endicott, 1983). This substitutive strategy reinforces the importance of affective and cognitive symptoms of depression while attenuating the role of neuro-vegetative symptoms.

The association between depression and its medical outcome has been studied extensively throughout the years (Smith, 2015). Traditionally, given the rapidly growing

body of statistics, the clinicians are advised to be watchful about depression while treating cancer patients (Nikbakhsh, Moudi, Abbasian, & Khafri, 2014; Smith, 2015). In fact, the secondary complications of the mood disorder should be seriously looked into (Mitchell et al., 2011). The initial feelings of weakness, sadness, and fears are often disabling, and the individual can eventually become depressed and suffer from anxiety (Jo¨nsson et al., 2016; Mitchell et al., 2011). The worrying aspect is that distress can turn into panic, social isolation and subsequently a crisis to treatment ensues (Jo¨nsson et al., 2016). According to a recent meta-analytic work, depression may enhance the mortality rate in the patients diagnosed with cancer (Pinquart & Duberstein, 2010; Prasad et al., 2014; Smith, 2015). The higher the level of psychological distress, the higher the rate of mortality in cancer sufferers (Batty, Russ, Stamatakis, & Kivimaki, 2017).

Three mechanisms have been proposed to elucidate how depression can lead to increased mortality (Spiegel & Giese-Davis, 2003). The first mechanism is its action on the neuroendocrine and neurological functions (Maes, Meltzer, Stevens, Calabrese, & Cosyns, 1994; Nordin, Berglund, Glimelius, & Sjödén, 2001; Raison & Mille, 2003; Reiche, Nunes, & Morimoto, 2004). It is thought that the presence of cancer modulates the mortality through an indirect pathway (Spiegel & Giese-Davis, 2003). Secondly, cancer patients suffering concomitant depression were more likely to default the oncology treatment and showed less engagement to the clinician's recommendation (Berry, Blonquist, Hong, Halpenny, & Partridge, 2015; de Souza et al., 2014; DiMatteo & Haskard-Zolnierek, 2010). By jeopardizing the treatment adherence to cancer treatment, depression can substantially enhance the cancer advancement. Conversely, promoting adherence attitude may become a more challenging task with progressively deteriorating health (Wagner & Ryan, 2004). Last but not least, there is the presence of overlapping symptoms of depression and cancer which then leads to making diagnosis difficult (Jadoon et al., 2010).

Research studies suggest that anxiety and depression in cancer patients might have different aetiologies (Polanski, Jankowska-Polanska, Rosinczuk, Chabowski, & Szymanska-Chabowska, 2016). Polanski et al. (2016) reported that the individuals may already have pre-existing anxiety and/or depression, while others experience episodes of mood changes in response to cancer. The difficulties in establishing a psychiatric diagnosis in cancer patients are confounded by the fact that there are no biological markers or physical signs to determine what is considered an 'appropriate sadness' in response to the terminal illness and what is a depressive illness (Lloyd-Williams, 2000). Hence, the undiagnosed depression may silently bring about the upsurge of mortality rate (Smith, 2015).

The depressed state can affect a person's thoughts, behaviours, feelings, and sense of well-being (D.M. Clarke, Cook, & Coleman, 2006; D.M. Clarke et al., 2005; D.M. Clarke, Smith, Dowe, & McKenzie, 2003). A depressed person may feel sad, anxious, empty, hopeless, helpless, worthless, guilty, irritable, and ashamed (American Psychiatric Association, 2013). In addition, anxiety often coexists with depressive disorders (Grotmol et al., 2017; Mystakidou et al., 2005). In patients with anxiety and depressive disorders, the symptoms are severe, with longer recovery times and poorer outcomes (Jadoon et al., 2010; Mystakidou et al., 2005). Interestingly, Meyer, Sinnott, and Seed (2003) found that patients with depression were more likely to have a recurrence of depression.

Depression results in a lower quality of life and reduced general wellbeing (Bardwell & Fiorentino, 2012; Bornbaum, Fung, Franklin, Nichols, & Doyle, 2012; Celik, Gorken, & Sahin, 2010; Smith, 2015). The quality of life of a cancer patient may be improved through proper oncology treatment. Despite this, the treatment side effects invariably result in various health-related concerns (Decat, de Araujo, & Stiles, 2011; Gogou et al., 2015; Goh, Steele, Jones, & Munro, 2013). Even when the cancer is treated, the accompanied physical and psychological complications (including depression) may offset the benefit of improved

quality of life acquired through the oncology treatment (Bardwell & Fiorentino, 2012; Duijts et al., 2014; Howard-Anderson, Ganz, Bower, & Stanton, 2012). Interestingly, the presence of undetected psychological distress may trigger subclinical conditions in the affected individuals (Batty et al., 2017).

In a local study among patients with breast cancer, C.G. Ng et al. (2017) found that more than half of the study patients had high levels of distress 6 months and a year after their diagnosis. The same study showed that the patients were likely to present anxiety compared to depressed mood.

2.4 Demoralisation in Cancer Suffers

2.4.1 Conceptualisation of Demoralisation

Many individuals diagnosed with cancer are confronted with a variety of problems (P. B. Jacobsen et al., 2005; A. Mehnert & Vehling, 2011). Numerous patients report distressing symptoms during the disease, which consequently affect the patients' quality of life (Decat Bergerot & Cavalcanti Ferreira de Araujo, 2014; A. Mehnert & Vehling, 2011).

Demoralisation has long been advocated as a hypothetically distinct psychiatric syndrome present in patients with terminal illness including cancer (Angelino & Treisman, 2001; D.W. Kissane et al., 2001). The syndrome has steadily gained importance. The justification behind its advocacy as a psychiatric syndrome is that demoralisation is connected to the desire for hastened death (Fang et al., 2014; Robinson, Kissane, Brooker, & Burney, 2016). Demoralisation is organised as an urgent and a potentially treatable condition (Robinson, Kissane, Brooker, & Burney, 2016).

Various research state that demoralisation is an affective state characterised by feelings of inadequacy, hopelessness, and helplessness (J. C. Jacobsen, Maytal, & Stern,

2007; D.W. Kissane et al., 2001). The individual feels that he or she is powerless, isolated, despairing, alienated, rejected, and has low self-esteem (J. de Figueiredo, M. & Frank, 1982). It is not surprising that the individual considers ending his or her life. Furthermore, it is a state often misunderstood, unrecognised or dismissed (J.M. de Figueiredo, 1993; D.W. Kissane et al., 2001; Robinson, Kissane, Brooker, & Burney, 2016), but has pertinent importance. A demoralised individual portrays an uncaring attitude to his or her life, which others might mistake them for being depressed (D.W. Kissane et al., 2001; D.W. Kissane & Kelly, 2000).

Many psychiatrists believed demoralisation is associated with an affective distress that is not specific to any particular psychiatric disorder (D.M. Clarke & Kissane, 2002; M. J. Clarke, 2011). Frank in 1961 first initiated the concept of demoralisation (J.M. de Figueiredo & Griffith, 2016). Frank (1974) mentioned that demoralisation is a result of the persistent failure of a person to cope with the internally or externally derived adversities. J.M. de Figueiredo (1993), and J. de Figueiredo, M. and Frank (1982) included the description of demoralisation as a state of ‘‘nonspecific’’ distress. D.M. Clarke and Kissane (2002) demonstrated that demoralisation is a distinctly defined syndrome of existential distress occurring in patients suffering from mental and physical illness. The distress occurs precisely when the individual faces a life-threatening situation or one’s integrity of wellbeing is being threatened (D.M. Clarke & Kissane, 2002; L. Grassi & Nanni, 2016; Robinson et al., 2015). J.M. de Figueiredo (1993), and J. de Figueiredo, M. and Frank (1982) further described the state occurs as the individual perceives himself or herself as being incapable of dealing proficiently with a specific stressful situation. Many scientists describe the state as a combination of distress and feelings of subjective incompetence (A. Mehnert, Vehling, Hocker, Lehmann, & Koch, 2011; Robinson, Kissane, Brooker, & Burney, 2016). Rudilla et al. (2016) proposed that sadness, anxiety, resentment, or anger are present and accompany the

distress and feelings of incompetence.

Engel (1967) firstly described the state the concept of the 'given-up complex.' D.W. Kissane et al. (2001) agreed with Engel's description as the state of hopelessness and helplessness occur in the medically ill. J. C. Jacobsen et al. (2006) further defined the individual perceives that he is failing himself and those close to him. As a result of the persistent awareness of having failed the expectation of others, the person develops poorer self-esteem (D.M. Clarke et al., 2006; D.M. Clarke et al., 2005; D.M. Clarke, Mackinnon, Smith, McKenzie, & Herrman, 2000). Frank (1974) reported that the self-esteem is damaged, and the person feels rejected by others because of his beliefs that he has failed to meet their expectations. D.M. Clarke et al. (2006) and D.M. Clarke et al. (2005) describe a sense of alienation and rejection which ensued. Alienation is a common occurrence and the individuals isolate themselves and withdraw from the environment (D.M. Clarke & Kissane, 2002; D.M. Clarke et al., 2005).

Accordingly, many researchers expanded the description of the state of demoralisation. Frank (1974) described the connection or shared ties with the surrounding people is often lost, therefore aggravating the reaction of the meaninglessness of life. The individual's strained or alienated ties with the valuable people he or she shares with, contribute to the sense of the meaninglessness of their lives. J. de Figueiredo, M. and Frank (1982) observed that demoralisation was a combined state of distress and subjective incompetence which co-exist with a fragile self-esteem. (D.M. Clarke & Kissane, 2002; D.M. Clarke et al., 2005). J.M. de Figueiredo (2007) further elaborated that the sentiment of the 'incompetent state' is despair, coupled with reduced coping skills. The individual feels trapped by a sense of powerlessness to plan or to initiate any action in order to achieve their goals and needs. In addition, J. de Figueiredo, M. and Frank (1982) painted the picture of a demoralised person as unmotivated and inhibited from all actions. The individual is left

feeling impotent, isolated, and in despair (Frank, 1974; J. C. Jacobsen et al., 2007). The resulting state of despair and a sense of incompetence results from an uncertainty about the directions that he or she needs to take (J. de Figueiredo, M. & Frank, 1982; J. C. Jacobsen et al., 2006).

In later years, demoralisation has been viewed differently as having a *psyche*-to-*soma* aetiological connection (Fava, Freyberger, & Bech, 1995). Using the Diagnostic Criteria for Psychosomatic Research (DCPR), the Italian investigators defined demoralisation as the failure to meet the expectations set by themselves and others, inability to cope with demands, sense of hopelessness, helplessness and a desire to give up (Sirri & Fava, 2013). Additionally, these specific feelings should be present for more than a month and antedate the development of medical disorders. These feelings must antedate the development of medical illness and/or exacerbate it (Sirri & Fava, 2013).

Nonetheless, despite more research conducted worldwide, the psychosomatic connection has gained less support (Epstein & Borrell-Carrio, 2005; Meissner, 2006; Tavakoli, 2009). Meissner (2006) postulated that the cognitive schemata and negative aspect of ones' assumptive world might have rooted since young, activated by the adversity of diseases in the later life. The medical illness and the treatment's side effects may be likely to precipitate the progression into demoralisation. The Australian psychiatrists placed less focus on the psychosomatic connection (D.W. Kissane et al., 2001). They think that it is hazardous to place a direct association between the psychosomatic notion and to omit the fact that various interactions between the *psyche* and *soma* can occur. Instead, a mutually reciprocal influence should be taken into the picture while looking at the causal-effect relationship (Tavakoli, 2009). Robinson, Kissane, Brooker, and Burney (2016) believed that the presence of a mild and moderate level of clinically relevant demoralisation does not influence the course of physical illnesses.

Demoralisation is regarded as a potentially treatable condition (D.W. Kissane et al., 2001). The progression into suicidality can be slowed or prevented by detecting the syndrome early and instituting an early and appropriate treatment. In order to formulate a more distinctive concept of demoralisation, a set of diagnostic criteria has been described to improve the identification of demoralisation (D.W. Kissane, 2000). It encompasses:

1. presence of emotional distress i.e., loss of meaning and hope in life,
2. experience of helplessness, pessimism, lack of worthwhile future,
3. reduction in the ability to cope and respond efficiently,
4. social alienation and deprivation from social support,
5. persistence of the symptomatology mentioned above for at least two weeks, and,
6. major depression should be ruled out exclusively,

McCormick and Conley (1995) reported the patients could feel the distress during any of the stages of cancer, i.e., the initial treatment, the time of treatment completion and hope for treatment success, the recurrence of cancer, the palliative treatment as well as the terminal stage of the disease. Many patients are uncertain about their social roles and tasks. The spiritual well-being and interactions with their family help them confront their impending death. (A. Mehnert & Vehling, 2011).

In conclusion, demoralisation is an abnormal state of existential despair (D.M. Clarke & Kissane, 2002; Parker, 2004; Robinson et al., 2015). Research has strongly suggested looking at demoralisation as a distinct and severe condition as demoralised patients are struggling to cope (D.M. Clarke & Kissane, 2002; Parker, 2004).

2.4.2 Demoralisation and Other Related Constructs

The literature has shown that demoralisation is distinct from depression (J. C. Jacobsen et al., 2006; Robinson, Kissane, Brooker, & Burney, 2016). D.M. Clarke et al. (2000) defined demoralisation syndrome as an existential distress arising in the patients anguished by their life-threatening mental and physical illnesses. L. Grassi and Nanni (2016) conceptualized that a demoralised individual perceives the source of their distress of arising externally. The individual does not feel guilty but feels subjectively incompetent to cope. J.M. de Figueiredo (1993) and J. de Figueiredo, M. and Frank (1982) further stressed that while the individuals do not have the existence of anhedonia and their motivation may be intact, they would be uncertain about the direction and what actions to take.

Accordingly, J. de Figueiredo, M. and Frank (1982) believed that the patients with depression identify the source of distress is within them. They have feelings of guilt and anhedonia and do not have the sense of motivation to want to do anything (American Psychiatric Association, 2013). D.M. Clarke et al. (2005) advocated that the demoralised patients are more distressed than the patients with anhedonic depression due to the presence of subjective feeling of incompetence and helplessness.

The demoralised patients can enjoy immediate pleasure prior to getting cancer, but they deny the pleasure due to helplessness and meaninglessness after the diagnosis of cancer (J. V. Jacobsen, LC; Block SD, Friedlander, RJ; Maciejewski, PK; Prigerson, HG 2006; D.W. Kissane et al., 2004; Robinson, Kissane, Brooker, & Burney, 2016; Strada, 2009). They perceive the future as hopeless in their current state of pessimism, helplessness, loss of purpose and meaning (D.W. Kissane et al., 2001). The depressed patients experience anhedonia, whereas demoralised patients experience subjective incompetence (J. C. Jacobsen et al., 2006). For many, it is a frightening experience (D.W. Kissane, 2004; Parker, 2004).

Many researchers believe that demoralisation can be somehow normative in the palliative patients depending on the extent of the impact of the medical illness (Sansone, 2010). Some researchers consider demoralisation as merely an adjustment disorder (American Psychiatric Association, 2013). Others believe it is no different from grief as a normal reaction to loss (Angelino & Treisman, 2001; Slavney, 1999). Additionally, there are considerable overlapping clinical features between depression and demoralisation making a clear delineation really challenging (Strada, 2009).

The rationale for demoralisation being the fundamental concept in the psychiatric literature of recent decades is that many of the medically ill patients develop the desire to die yet do not exhibit symptomatology of clinical depression (D.M. Clarke & Kissane, 2002; D.W. Kissane et al., 2001). L. Clarke, Ungerer, Chahoud, Johnson, and Stiefel (2002) and Strada (2009) further described a depressed person as losing the ability to experience pleasure; while a demoralised person is unable to look forward due to the presence of helplessness and feeling incompetent, with a desire to die. D.W. Kissane (2000) suggested existential distress present in demoralisation hastens the progression of desire to die.

Another important concept associated with demoralisation is hopelessness. Hope is an essential, fundamental and integral part of life (D.M. Clarke & Kissane, 2002). Frankl (1973) and Kubler-Ross (1969) describe when hope disappears, death ensues. Many studies view hopelessness as a primary predictor of suicidal behaviours (Bagge, Lamis, Nadorff, & Osman, 2014; Campos, Holden, Laranjeira, Troister, & Oliveira, 2016; Klonsky, Kotov, Bakst, & Rabinowitz, 2012). Importantly, it is indeed a much stronger predictor than depression for suicidality. Frank (1974) demonstrated that the core reason for the presence of demoralisation is a breakdown of coping mechanism. Frank (1974) reported that when the individuals perceive the threat or a challenge, they have inadequate resources to respond. Their appraisal is affected by the beliefs, values and commitments as well as their sense of general optimism

or pessimism, and self- efficacy (D.M. Clarke et al., 2000). The sense of independence and competence is affected by the physical and mental ill health. A sense of hopelessness can occur when the condition persists, does not respond to treatment, or there is no treatment (D.M. Clarke et al., 2000; L. Grassi & Nanni, 2016; Robinson et al., 2015).

2.4.3 Measuring Demoralisation

There are two ways to detect demoralisation. The first method is to use Diagnostic Criteria for Psychosomatic Research (DCPR) developed by Fava et al. (1995). Fava et al. (1995) viewed demoralisation as having a *psyche*-to-*soma* aetiological connection. Using this diagnostic criteria (DCPR), the Italian investigators defined demoralisation as the failure to meet the expectations set by themselves and others, inability to cope with demands, sense of hopelessness, helplessness and a desire to give up (Sirri & Fava, 2013).

However, with more research conducted worldwide, the psychosomatic connection in demoralisation has gained less support (Epstein & Borrell-Carrio, 2005; Meissner, 2006; Tavakoli, 2009). The Australian psychiatrists placed less focus on the psychosomatic connection (D.W. Kissane et al., 2001). They think that it is hazardous to place a direct association between the psychosomatic notion and to omit the fact that various interactions between the *psyche* and *soma* can occur. Instead, a mutually reciprocal influence should be taken into the picture while looking at the causal-effect relationship (Tavakoli, 2009).

D.W. Kissane et al. (2004) developed the Demoralisation Scale (DS) to facilitate determining the presence of demoralisation in patients with advanced cancer. D.W. Kissane et al. (2004) considered 24-item self-report assessing demoralisation with a collection of 32 items originating from their clinical observations. The aim was to confirm the existence of demoralisation and assist treatment in palliative care. These researchers designed the scale in an attempt to confirm the existence of demoralisation in order to commence treatment. The

researchers conducted their initial construction and validation of the questionnaire among 100 patients with advanced cancer and used five facets, as the factor structure. The factors studied involved the loss of meaning in life, dysphoria, disheartenment, helplessness, and sense of failure. Subsequently, several authors adapted and validated the Demoralisation Scale into several different languages (Costantini et al., 2013; Hadnagy, Csikós, & Nagy, 2012; Hung et al., 2010; A. Mehnert et al., 2011; Mullane et al., 2009; Robinson, Kissane, Brooker, & Burney, 2016; Rudilla et al., 2016).

These studies concluded the DS is a valid and reliable instrument in its usage among patients with advanced cancer. The results of the studies provided more evidence to support and confirm the theory that the demoralisation state differs from a depressive state. The conclusion of the numerous literature review is that demoralisation is always abnormal and requires intervention (Angelino & Treisman, 2001; Robinson et al., 2015). Subsequently, DS is mostly used to assess for demoralisation in palliative care (Rudilla et al., 2016).

2.5.0 Positive Emotion

2.5.1 Emotional Regulation and Negative Emotion

Clinicians tend to concentrate more on the treatment of depression while the primary and secondary prevention strategies are frequently overlooked (Ng & Hazli, 2016). Treatment should emphasize on human qualities rather than the illnesses and weakness (M.E. Seligman & Csikszentmihalyi, 2014). The present psychological treatment focuses mainly on the alleviation of the symptomatology of mental disorders instead of instilling human positives (Carl, Soskin, Kerns, & Barlow, 2013; M.E. Seligman & Csikszentmihalyi, 2014).

An emotion begins with an individual's assessment of the personal meaning of

antecedent events (Diener, 1999; Fredrickson, 2001). There is a multicomponent response unfolding over a relatively short time span (Diener, 1999; Fredrickson, 2001).This appraisal process may be either conscious or unconscious. This, in turn, triggers a cascade of response tendencies manifesting across loosely coupled component systems, such as subjective experience, facial expression, cognitive processing, and physiological changes (Diener, 1999; Fredrickson, 2001).

Emotion regulation is essential and has a significant role in mental health, particularly in people with a major depressive disorder (Carl et al., 2013; Fredrickson & Joiner, 2002; Werner-Seidler, Banks, Dunn, & Moulds, 2013). Emotion regulation refers to the processes used by individuals to influence how their emotions are experienced and expressed (Diener, 1999; Fredrickson, 2001; J. J. Gross, 1998). Emotion regulation refers to both the conscious and unconscious processes which then influence the occurrence, intensity, duration, and expressions of emotion (L. Campbell-Sills, D.H. Barlow, T.A. Brown, & S.G. Hofmann, 2006a; J. J. Gross, 2002). J. J. Gross (2002) proposed that the individuals regulate their emotions cognitively or behaviourally.

The presence of depressed mood and anhedonia are related to deficits in the emotional regulation (Campbell-Sills et al., 2006a; J. J. Gross, 2002). Disturbances in emotion regulation are seen and affect the many phases of depression (Ehring, Fischer, Schnülle, Bösterling, & Tuschen-Caffier, 2008; Ehring, Tuschen-Caffier, Schnülle, Fischer, & Gross, 2010). When a sad mood is induced or triggered, depression-vulnerable individuals frequently suppress their emotions and use less of their reappraisal (Ehring et al., 2010; Raes et al., 2014). The subsequent state is the maintenance of negative emotions triggered by adverse life events or on-going cognitions (Ehring et al., 2010). Being depressed is not only

characterised by an increase in the negative affect but also by a decrease in positive affect or a diminished ability to respond to the positive affect (Raes et al., 2014).

Several other researchers supported the hypothesis of emotional dysregulation is depression (Feldman, Joormann, & Johnson, 2008; J. Joormann, 2010; J. Joormann & Gotlib, 2010; Raes, Daems, Feldman, Johnson, & Van Gucht, 2009). Previous studies showed that depression is linked to a failure to restrain valence information negatively and to heightened stages of recurring negative thinking, e.g., rumination (J. Joormann, 2010; J. Joormann & Gotlib, 2010). Other evidence showed that depressive symptoms are associated with efforts to dampen and reduce the positive affects (Feldman et al., 2008; Raes et al., 2009).

Interestingly, several studies showed the level of current (L. Campbell-Sills, D.H. Barlow, T.A. Brown, & S.G. Hofmann, 2006b; Ehring et al., 2010) and past depressive (Ehring et al., 2008) symptomatology play substantial roles in affecting the emotional regulation. The deficits in emotional regulation are related to more negative moods, worsening interpersonal functioning, and higher levels of psychopathology (Ehring et al., 2010; Moore, Zoellner, & Mollenholt, 2008). Negative emotions are reported to unconsciously disregard the positive emotions, such as joy, interest, contentment, and love (Fredrickson, 1998).

2.5.2 Positive Emotion and Positive Psychology

Feelings influence cognitive processes. Thus, fluctuations in feelings can systematically affect the cognitive processing (Ashby & Isen, 1999; A.M. Isen, Daubman, & Nowicki, 1987). Not all symptoms of depression are treated effectively by pharmacological and psychological therapies (Dunn, 2012; Ehring et al., 2008; Raes et al., 2014). Similar to

negative emotions, positive emotions are vital to human nature and contribute deeply to the quality of people's lives (B.E. Compas & Luecken, 2002; Fredrickson, 1998; Greene & Noice, 1988). In recent years, research showed that working with vulnerable individuals and building their positive emotions may protect the persons from an initial episode of depression or subsequent relapses (C.G. Ng et al., 2017; M. M. Tugade & Fredrickson, 2004; M.M. Tugade, Fredrickson, & Feldman Barrett, 2004; Werner-Seidler et al., 2013). Thus, improving their psychological adjustment and resilience are important (Gilbert et al., 2016; M. M. Tugade & Fredrickson, 2004).

Clinical research has placed much attention on studying the negative emotions while ignoring the field of positive emotion (Fredrickson & Joiner, 2002; Fredrickson & Losada, 2005). The possible reasons are that positive emotions are fewer in number and somewhat diffused (Fredrickson, 1998). Scientists had identified only one positive emotion for every three or four negative emotions (Ellsworth & Smith, 1988). Moreover, negative emotions pose a vast array of problems for individuals and society, while positive emotions pose just a few (Fredrickson, 1998). Fredrickson (1998) identified four different types of positive emotions namely joy, interest, contentment, and love. Research suggests positive affect may influence the organisation of cognitive material which then promotes creative thinking and facilitate problem-solving (Fredrickson, 1998; Greene & Noice, 1988; A.M Isen, Niedenthal, & Cantor, 1992). Interestingly, Greene and Noice (1988) found that having positive affect resulted in the individuals being able to recombine cognitive elements, i.e., having various ideas and concepts. Similar findings were revealed by A.M Isen et al. (1992). Greene and Noice (1988) discovered positive cognitive performances stimulated positive emotional states. While Murray, Sujan, Hirt, and Sujan (1990) revealed that the people experiencing positive affect were more flexible. A.M. Isen et al. (1987) added that positive affect facilitates memory. Having positive feelings as well allows changes in the strategies used in

decision-making tasks (Greene & Noice, 1988; A.M. Isen et al., 1987).

A systemic review paper proposed that the strategies of positive psychology such as increasing positive emotion and developing personal strengths are immensely useful tools for the prevention and treatment of depression (Santos et al., 2013; Werner-Seidler et al., 2013). Interestingly, studies show positive thinking is a vital strategy to cope with cancer (Gilbert et al., 2016). Fredrickson (1998) believed having positive emotions can undo the aftereffects of negative emotions and thus protecting one's health.

M.E. Seligman and Csikszentmihalyi (2014) defined positive psychology as the psychological approach targeting the person's skills in promoting positive cognitive functioning in addition to the physical and emotional health. Seligman conceptualized the idea of positive psychology in 1998, and the field has expanded since then (Aspinwall & Tedeschi, 2010; Fredrickson, 2001; M.E. Seligman, Steen, Park, & Peterson, 2005). M.E. Seligman and Csikszentmihalyi (2014) stated the presence of positive emotions is imperative to a person's strengths and skills. Positive psychology is primarily meant to incorporate positive emotions such as gratitude, serenity, joy, love, pride, amusement and other positive emotions, into the individuals' functioning (Sin & Lyubomirsky, 2009; Wood & Tarrier, 2010).

M.E. Seligman et al. (2005) stated positive psychology is an umbrella term for the study of positive emotions, positive character traits, and enabling institutions. M.E. Seligman and Csikszentmihalyi (2014) incorporated three matters: positive experience, optimistic personality, and encouraging communities and institutions. Many of the constructs are related to health namely sense of coherence, and optimism (Aspinwall & Tedeschi, 2010). M.E. Seligman and Csikszentmihalyi (2014) elaborated that the field of positive psychology occurs as a subjective experience incorporating the individual's well-being in the past, present and

for the future. The process targets emotions such as contentment, and satisfaction (in the past); cheerfulness (in the present); hope and optimism (for the future).

Additionally, the field of positive psychology emphasizes the family and the community are significant associations which allow the experience and expression of positive emotions to enhance a person's mental health and promote wellness (M.E. Seligman & Csikszentmihalyi, 2014; M.E. Seligman et al., 2005). The focus of therapy in the individuals looks at the positive traits such as the capacity for love and vocation, courage, and interpersonal skill and wisdom. Research by Fredrickson (1998), Cohn and Fredrickson (2010) and several others suggest that the presence of positive emotions broaden the individual's attention, cognition, and behavioural repertoires. Having such repertories helps the individuals to develop lasting and personal resources.

Some clinical psychological treatments for depression are formulated based on the evidence from clinical researches on positive psychology. Positive psychotherapy (PPT) is one of the model interventions to instil positive emotion, behaviour, and cognition (Seligman, Rashid, & Parks, 2006); and helps to generate more adaptive coping strategies in the efforts to alleviate depressive symptomatology and preventing relapse (Seligman, Parks, & Steen, 2004). The individuals' experiences of positive affect will prompt the individuals to engage with their environments and partake in activities, which are adaptive for the individuals (Fredrickson, 2001).

2.5.3 Positive Emotion in Patients with Cancer

Researchers believed that a positive emotion does not only play a pivotal role in the treatment of depression but also provides some protection towards stress and depression (Sin

& Lyubomirsky, 2009; Wood & Tarrier, 2010). Health professionals believe that using positive psychology interventions will help patients broaden their thought-action repertoires and integrate these new behaviours into their daily lives (Cohn & Fredrickson, 2010; Wood & Tarrier, 2010). Several findings suggest positive emotions predict many desirable short- and long-term outcomes (Casellas-Grau, Vives, Font, & Ochoa, 2016; Cohn & Fredrickson, 2010; Wood & Tarrier, 2010). The development of the field of positive psychology suggested that individuals are able to handle their distress based on a balanced and heightened focus on the positive aspect of their lives (Wood & Tarrier, 2010).

Similarly, in the work with cancer patients, the field of positive psychology has raised much interest. Dunkel-Schetter, Feinstein, Taylor, and Falke (1992) and Carver et al. (1993) found lesser emotional distress in cancer patients using patterns of coping that focus on the positives. Other studies showed similar results (Carver, Smith, Antoni, Petronis, & Derhagopian, 2005; B.E. Compas et al., 1999; Epping-Jordan et al., 1999; Helgeson, Snyder, & Seltman, 2004; Lepore & Helgeson, 1998; Osowiecki & Compas, 1999; Stanton et al., 2000). Epping-Jordan et al. (1999) revealed similar findings to Carver et al. (1993) in which that optimism played a key role in predicting coping and emotional distress among the subjects with breast cancer. Osowiecki and Compas (1999) observed that the problem-focused engagement coping and perceived control predicted better adaptation to the diagnosis of breast cancer and lower anxiety/depression symptoms.

Interestingly, according to B.E. Compas et al. (1999), in the psychological adjustment of women with breast cancer, younger women displayed greater affective distress and tended to engage in less adaptive ways of coping. Stanton et al. (2000) showed that among patients with breast cancer, handling their distress through actively processing and expressing emotions served as a satisfactory way to reduce their anguish. Helgeson et al. (2004) found

that psychological and physical adjustment in breast cancer subjects correlated with younger age, the presence of optimism, perceived control and social resources. Similar findings were seen by Lepore and Helgeson (1998) among prostate cancer survivors. In the survey, the subjects who avoided speaking about their condition and those with poor social support had poorer mental health status.

Carver et al. (2005) and Zuraida, Zainal, and Ng (2014) found that the presence of initial optimism and marital status predicted psychological well-being in survivors of breast cancer. Being optimistic motivates patients to approach and continue participating in the environment which is useful for them at the moment they are receiving treatment. Aspinwall and Tedeschi (2010) proposed that the researchers and practitioners develop interventions promoting positive psychology despite the patients showing modest or no evident influence on the disease's progression. It was not surprising as research has proven the experiences of positivity affect the individuals to participate in activities and be involved with their environment that has significant consequences on their state.

2.5.4 Measuring Positive Emotion

Given the robust evidence about the significance of positive psychology, there is a need to objectively measure the presence of positive emotion particularly in a vulnerable group of patients such as those with cancer or having a terminal illness. Considering the potential therapeutic importance of positive emotion, especially in the cohort of depressed individuals (T. A. Brown, 2007; Dunlop & Nemeroff, 2007; Treadway & Zald, 2011), C. G. Ng and Hazli (2016) led a pilot study conducted in Universiti Malaya Medical Centre (UMMC) to develop Positive Emotion Rating Scale, an assessment tool to measure positive emotions (C. G. Ng & Hazli, 2016).

The expert panel discussion was conducted to determine the components of scale. The panel also referred to other relevant scales such as Snaith-Hamilton Pleasure Scale (Snaith et al., 1995) in the item selection process. The preliminary PERS was tested in the pilot study and 8 items were finalized and included in the scale. These eight items in PERS were designed based on 6 domains, which comprised active, interest, gratification, contentment, pride and love. The 5-point Likert scale is used to indicate the frequency of the symptoms, ranging from 1 (never) to 5 (always). The test's score ranges from 8 to 40. The higher score of the scale indicates a higher level of position emotion. The cut-off point of 30 and above is set to efficiently differentiate the depressed patient from the healthy counterpart.

PERS exhibited outstanding psychometric properties to be used as a valid and reliable psychological instrument for assessing positive emotion. PERS presented an impressive internal consistency with high Cronbach's alpha value (0.9), which denoted a considerable agreement among the scale items within the instrument (C. G. Ng & Hazli, 2016). Besides, PERS was also shown to have enough discriminant ability against CES-D, which measures depression (Radloff, 1977). High concurrent validity with Snaith-Hamilton Pleasure Scale was demonstrated with Spearman's correlation, r, of 0.805 (p>0.01).

CHAPTER 3: RATIONALE, OBJECTIVES AND RESEARCH HYPOTHESIS

3.1 Rationale of the study

Demoralisation is a concept frequently encountered in an oncology setting especially in patients with advanced cancer. It is a psychological condition that is potentially treatable but frequently neglected by the clinicians in the daily clinical practice. Generally, the clinicians pay more attention to the illness or other negative emotion such as depression, rather than assess and address the concern of demoralisation. Hence, the physicians need to promptly identify the emotional state of demoralisation, as it may progress into more serious psychiatric conditions or complications such as suicide.

To date, there is no data on demoralisation amongst patients with cancer in Malaysia. One reason was that there was no Malay translated version of the Demoralisation Scale to assess the prevalence of demoralisation syndrome in local patients. In Malaysia, the Malay Language is the official and primary language. Therefore, a translated and validated Malay version of the Demoralisation Scale is very important.

3.2 Objectives of the Study

The objectives of this study are:

1. To study demoralisation in cancer patients.
2. To examine the association of positive emotion with demoralisation in cancer patients.
3. To examine the association between demoralisation and depression in cancer patients.
4. To study other associated factors in relation to demoralisation in cancer patients.
5. To investigate the psychometric properties of the Malay version of the Demoralisation Scale.

3.3 Research Hypothesis

Demoralisation is positively associated with depression and distress level among cancer patients. Positive emotion is inversely associated with the state of demoralisation in cancer patients. Sociodemographic, disease and treatment-related variables are related to the state of demoralisation.

CHAPTER 4: METHODOLOGY

4.1 Study Design and Sample

The study is a cross-sectional study conducted in Universiti Malaya Medical Centre (UMMC), Kuala Lumpur, Malaysia. The studied subjects were recruited from the oncology ward, day-care clinic, and follow-up clinics from January to December 2017.

4.2 Sample size calculation

The sample size calculation was based on the formula purposed by Daniel (1999). Robinson et al. (2015) claimed that the prevalence of demoralisation was estimated to be about 13% to 18% in the patients at various stages of cancer (n=2295). In the present study, the prevalence rate of 13% (Mullane et al., 2009) was adopted to determine the sample size.

$$n = \frac{Z^2 P (1 - P)}{d^2}$$

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: Desired precision set at 0.05.

Thus **n: $(1.96)^2$ x (0.13) (1-0.13) / 0.05^2= 174**

4.3 Enrolment Criteria

4.3.1 Inclusion criteria:

1. The enrolled subjects must be at least 18 years old and attending the follow-ups at the oncological clinic, day-care unit or wards, UMMC.
2. The diagnosis of cancer could be of any type, stage and duration since they first receive the diagnosis.
3. The subjects must be able to understand both the English and Malay languages with the capability to complete a battery of self-report measures.
4. They must provide the written consent in order to partake in the study.

4.3.2 Exclusion criteria:

1. Those who have intellectual disability, dementia, acute medical condition (e.g. delirium) or acute psychosis were excluded from the enrolment.
2. Those who refused to give informed consent.

4.4 Translation Process

As there was no Malay adaptation of the Demoralisation Scale, a Malay translated version was constructed. As suggested by the World Health Organization (2018) and Beaton, Bombardier, Guillemin, and Ferraz (2000), the translation of the Demoralisation Scale from English into the Malay Language involved the forward and backward translation processes. In the forward translation, the researcher translated the original measure into the Malay Language. The preliminary version was then checked for wording adequacy and grammatical errors. Subsequently two medical doctors executed the backward translation; the researcher requested that they translated the Malay Version of the Demoralisation Scale back into the

English Language. The product from the backward translation was compared with the original English version to detect any difference.

Face validity of the DS was tested on twenty respondents who were selected from those accompanying the cancer patients in the oncological setting. The selected subjects were asked to go through the Malay translated version. Subsequently, they were inquired if they fully understand the measures and meanings. No individual reported difficulty in responding to the instruments.

4.5 Assessment Tools

4.5.1 Sociodemographic and Clinical Characteristic Questionnaire

The questionnaire is to collect data comprising age, gender, race, marital status, employment status, the highest level of education, types of cancer, duration since diagnosis, comorbid medical, surgical or psychiatric illness.

4.5.2 Positive Emotion Rating Scale (PERS)

PERS is a newly developed tool to measure positive emotion especially in patients with depression (Guan et al., 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 minimally 8 to a maximal 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. PERS has a high discriminant validity towards Snaith-Hamilton Pleasure Scale (SHAPS) & Centre for

Epidemiologic Studies Depression (CESD) Scale. It has excellent internal reliability with the Cronbach's Alpha value of 0.9.

4.5.3 Distress Thermometer (DT)

The DT is a visual analogue scale designed to measure the level of emotional distress in cancer patients (Roth et al., 1998). DT is presented in a form of the thermometer as a step to destigmatize 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. Depending on the validation tools or diagnostic criteria employed, the optimal cut-off points of either 4 or 5 is used to clinically distinguish significant distress from that of the rest (Vodermaier et al., 2009). A local validation study of the Malay version of DT has advocated a cut-off point of 5 to indicate a higher level of psychological distress (Yong, Zubaidah, Saidi, & Zailina, 2012).

4.5.4 Centre for Epidemiologic Studies Depression (CESD) Scale

The Centre for Epidemiologic Studies Depression (CESD) Scale has long been organised to be an excellent instrument to screen for depressive symptomatology in cancer patients (Vodermaier et al., 2009). The original English version of 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.

Across studies, the CES-D has been showed to have high internal consistency with Cronbach's α coefficients ranging from .85 to .90 (W.M. Hunter et al., 2003; W. M. Hunter et al., 2003; Radloff, 1977). Additionally, its concurrent and construct validity have also been evinced to be adequate. In a work of systematic review examining the assessment instruments used in screening for emotional distress among cancer patients, CES-D was revealed to possess high reliability, criterion measure, validity and excellent judgement (Vodermaier et al., 2009). CESD was also available in the Malay Language as well (Zuraida et al., 2014).

4.5.5 Demoralisation Scale (DS): English version

The DS is a self-administered tool to measure the construct of existential distress based on the demoralisation syndrome (D.W. Kissane et al., 2001; D.W. Kissane et al., 2004). It contains 24 items and uses a 5-point Likert scale to evaluate the degree to which the respondents agree to each item. The response categories indicate the frequency of occurrence, and it ranges from 0 (never) to 4 (all the time). Through principal factor analysis, DS is revealed to have five-factor structures, i.e. loss of meaning in life (5 items, $\alpha = 0.83$), dysphoria (5 items, $\alpha = 0.77$), disheartenment (6 items, $\alpha = 0.82$), helplessness (4 items, $\alpha = 0.85$) and sense of failure (4 items, $\alpha = 0.68$). The total score is collected by summing up the score of each item and it can range from 0 to the maximum score of 96. In the original Australian research studying palliative cancer subjects, a cut-off score of >30 is employed to indicate high demoralisation (mean score = 30.82; SD = 12.73) (D.W. Kissane et al., 2004). However, a subsequent validation using Irish patients has shown a much lower score to distinguish the high level of demoralisation (mean = 19.94; SD = 14.62) (Mullane et al., 2009).

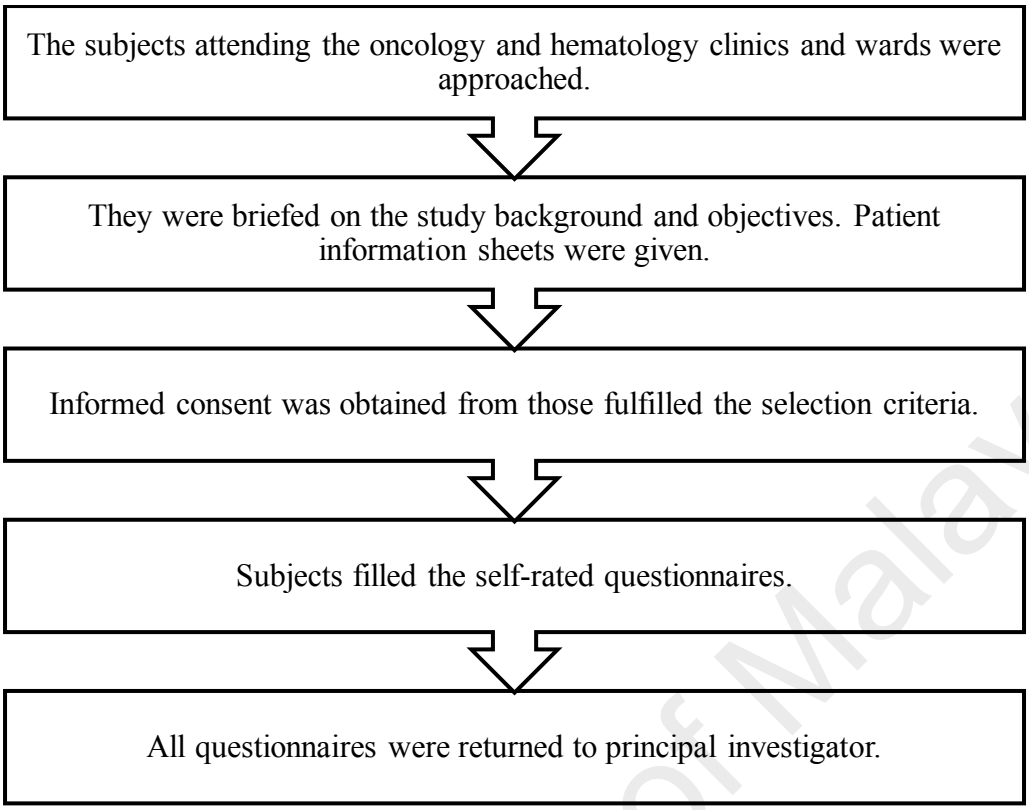
4.5.6 Malay version of Demoralisation Scale (DS-M)

DS-M is created via the backward and forward translation process based on the original version of DS (D.W. Kissane et al., 2004). Similar to its original version, the newly translated DS-M contains 24 items that use a 5-point Likert scale to evaluate the frequency of the symptoms. The frequency of the occurrence ranges from never (0), seldom (1), sometimes (2), often (3) to all the time (4). Five of these 24 items, i.e. item 1, 6, 12, 17 and 19, have reverse scorings. In these reversely coded items, a response of 'all the time' indicates score 0, 'often' indicates score 1, 'sometimes' indicates score 2 and so forth. The total score is calculated by summing up the score of each item. The higher score reveals a higher level of demoralisation.

4.6 Study Procedure

The patients attending the oncology and haematology clinics and wards in Universiti Malaya Medical Centre were conveniently approached and the purpose of the study and other relevant information such as the participants' right and confidentiality were explained to them. The participants were selected based on the inclusion and exclusion criteria. The recruited subjects would be given patient information sheet to ensure they were fully informed about the study. Written consent was obtained before the commencement of the study. They were given the basic instructions on how to answer these self-reported measures. The average time taken to complete the questionnaires was about 15 minutes.

Flowchart of Study Procedure



4.7 Statistical Analysis

The data collected from the study was computed and analysed using the latest SPSS version 24.0. Descriptive statistics were employed to summarize the clinical and sociodemographic characteristics of the patients. The data obtained from the Demoralisation Scales (DS and DS-M), Distress Thermometer (DT) and Positive Emotion Rating Scale (PERS) were also tabulated and analysed. The correlations between DS-M with Distress thermometer (DT), CESD, PERS and DS (English version) were tested using Spearman's correlation analysis. Chi-square tests on the low and high demoralisation groups with other associated factors were conducted to examine their relationships and significance. The significant findings would be further analysed using multivariate logistic regression.

A principal component analysis (exploratory factor analysis, EFA) with varimax and

oblique rotation were performed (n=178). This procedure was to examine the factor structures of the DS-M. Item analyses such as internal consistency (within subscale and total scale) and intra-class correlation (between each corresponding item from DS and DS-M) were explored. They were expressed in the Cronbach's alpha coefficient, α, and Spearman's correlation coefficient, r, respectively. All the tests were two-tailed with a significance level 0.05. Finally, the cut-off value of DS-M was calculated based on the plot of sensitivity against the function of 1-specificity in the Receiver Operating Characteristic (ROC) curve.

4.8 Ethical Approval

The Medical Research Ethics Committee of Universiti Malaya Medical Centre (UMMC) reviewed the research protocol and approved the study on 29 January 2017. The MREC ID number was 20161031-4462. The data collection commenced only after obtaining the approval from the Medical Research Ethics Committee.

Informed consent must be obtained from the subjects prior to the commencement of study process. Information pertaining to the study's background and related objectives were explained by the investigator. The patient information sheets containing information about the patients' right and confidentiality were also provided. They were also informed that they could withdraw from the study at any time and their personal data would not be revealed to athird party. For those who were screened positive for psychological distress, they were advised to attend the psychiatric walk-in clinic.

CHAPTER 5: RESULTS

5.1 Sociodemographic and Clinical Information

One hundred and seventy-eight patients with cancer were recruited. The average age of these subjects was 53.6 years old (SD=16.51; range=18-86). The recruited patients were predominantly females (64%) whereas only 36% of the participants were male. 42.1% of the participants were Chinese followed by Malay (39.9%), Indian (13.5%) and others (4.5%). The majority of the participants were Muslims (41%), and it was followed by Buddhists (27.5) and Christian (15.2%). In 96.1% of the subjects received at least a secondary education. One third of the participants had a full-time employment at the time of interview. Another 2/5 of them were either retirees or pensioners.

Table 2 demonstrates the clinical characteristics of the participants. Approximately 22% of the subjects were recently diagnosed to have cancers (less than 6 months). 40% of the subjects had breast cancer of various stages. One fourth of the subjects had advanced stage of disease (24.2%). It was followed by stage III (25.8%), II (16.3%) and I (11.2%). 63.5% of the participants reported no prior history of medical illnesses. The remaining had reported various medical disorders such diabetes mellitus, hypertension, dyslipidaemia, renal disease and so forth. Only 4.5% of the participants had the history of depression.

Table 1: Sociodemographic Characteristic of Cancer Patients.

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)
Buddhism	49 (27.5)
Christian	27 (15.2)
Hindu	20 (11.2)
Others	9 (5.0)
Education, n (%)	
Primary	7 (3.9)
Secondary	79 (44.4)
Tertiary	92 (51.7)
Marital Status, n (%)	
Single	44 (24.7)
Married	127 (71.3)
Divorced	4 (2.2)
Widow	3 (1.7)
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)

Table 2: Clinical Profile of Cancer Patients.

Variables	n (%)
Cancer Type	
Breast	68 (38.2)
Gastrointestinal	24 (13.5)
Hepatobiliary	22 (12.4)
Genitourinary	27 (15.2)
Hematological	12 (6.7)
Others	25 (14.1)
Stages of Cancer	
I	20 (11.2)
II	29 (16.3)
III	46 (25.8)
IV	43 (24.2)
Unspecified	40 (22.5)
Duration of Diagnosis	
≤6 months	39 (21.9)
6 months to 1 year	53 (29.8)
1 year to 5 years	58 (32.6)
>5 years	28 (15.7)
Medical Illness	
Hypertension or DM	57 (32.0)
Others	8 (4.5)
Not known	113 (63.5)
Psychiatric Illness*	
Yes	8 (4.5)
No	170 (95.5)

5.2 Descriptive Analysis of the Scales' Score

In this study, both English and Malay-translated versions of Demoralisation Scales were used. The descriptive summary of the scores for each item was tabulated in Table 3. The mean score of each corresponding item from both versions were similar. The means of the total score for the original DS and DS-M were similar, i.e. 18.79 (SD=15.30). Intra-class

correlation between each scale item category will be discussed under the section '*reliability testing'*.

Table 3: Intra-Class Correlation between Each Corresponding Item from Both Versions of Demoralisation Scale.

Items	English Version		Malay Version		Cronbach's alpha	Intra-Class Correlation	*p*-value
	Mean	SD	Mean	SD			
1	1.18	1.03	1.20	1.08	.98	.97	<0.01
2	.57	.82	.59	.83	.99	.98	<0.01
3	.63	.84	.63	.84	.99	.99	<0.01
4	.59	.89	.61	.90	.99	.99	<0.01
5	.79	.95	.81	.98	.99	.98	<0.01
6	.98	1.02	.97	1.03	.94	.89	<0.01
7	.62	.89	.63	.95	.98	.95	<0.01
8	.67	.96	.66	.99	.98	.96	<0.01
9	.44	.72	.46	.76	.99	.98	<0.01
10	.58	.86	.60	.90	.96	.92	<0.01
11	1.04	1.05	1.11	1.10	.93	.96	<0.01
12	1.16	1.11	1.12	1.11	.97	.95	<0.01
13	.79	.93	.81	.96	.95	.91	<0.01
14	.37	.69	.40	.72	.96	.93	<0.01
15	.91	.90	.89	.89	.96	.93	<0.01
16	1.04	1.04	1.02	1.01	.98	.95	<0.01
17	1.04	1.04	1.04	1.05	.98	.96	<0.01
18	1.12	1.01	1.10	1.02	.98	.97	<0.01
19	1.06	1.10	1.07	1.08	.99	.98	<0.01
20	.32	.71	.29	.65	.95	.90	<0.01
21	.69	.90	.68	.89	.99	.97	<0.01
22	.70	.91	.71	.93	.99	.98	<0.01
23	.65	.98	.63	.98	.99	.99	<0.01
24	.75	.99	.75	1.00	.99	.97	<0.01

Abbreviation: DS=Demoralisation Scale; SD=standard deviation

Table 4 described the ranges, means and standard deviations of the scores obtained from DS-M, PERS, CES-D and DT. The participants were also categorised according to the different cut-off points respectively and were shown in the form of percentage.

DS-M was categorized into high (score of 23 and above) and low (score lower than 23) level of demoralisation. The mean of the DS-M's total score was 18.79 (SD=15.30). Out of 178 subjects, 67 patients (37.6%) demonstrated high level of demoralisation. 62.4% of them had scored lower than 23 in DS-M.

On the other hand, the mean score for PERS was 33.53 (SD=6.22). 25.3 % of the subjects had scored less than 30, which indicated lower positive emotion. One hundred and thirty-three patients (74.7%) were categorized into the group of higher positive emotion (score 30 and above).

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. The remaining subjects (74.7%) had scored 15 and below and thus was classified as non-depressed.

Distress Thermometer was categorized into high (score of 4 and above) and low (score of 3 and below) distress groups. The mean score of DT was 3.07 (SD=2.01). As high as 38.8% of the individuals revealed high degree of distress. There were 109 patients (61.2%) were classified under low-distress group.

Table 4: 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)

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.

5.3 Factor Structure

Principal factor analysis with a varimax rotation has concluded that DS-M containing 4 primary factors with eigenvalues of 11.32, 1.85, 1.20 and 1.03. The percentages of variance explained by these 4 factors were 47.17, 7.73, 4.99 and 4.28, respectively, accounting for 64.17% of the total variance. Factor loadings were shown in Table 5. All of the five factor solutions had indicated excellent level of internal consistency with value of Cronbach's alpha ranging from .81 to .92.

For the first factor, it had 10 items and was termed 'disheartenment.' The items included 8, 9, 10, 11, 14, 21, 22, 23 and 24. The internal consistency recorded as high as 0.924. The second factor contained 5 items and is termed 'loss of meaning and purpose'. Item 2, 3, 4, 5 and 7 were grouped in the second subscales. It had attained a good internal consistency with Cronbach's alpha value of .87.

The third factor expressed the loss of role and life value, feeling of helplessness and regret in life (α=.81). Hence, it actually reflects 'sense of failure.' All of the items which were reversely scored, were included in this subscale. The forth subscale captured the non-specific characteristics of negative emotion, which was termed 'dysphoria' (α=.83). It comprised feeling of regret, getting hurt easily, angry and distress.

Table 5: Principal Components Factor Analysis of the 24 Items (Varimax and Kaiser Normalization) Generating a 4-Factor Solution after 12 Iterations.

Item No.	Item Contents	Principal Factors*			
		1	2	3	4
8	Self-help/*bantu sendiri*	**.568**	.403		
9	Hopeless/tiada harapan	**.647**	.354		
10	Guilty/*bersalah*	**.608**	.345		
11	Irritable/*senang marah*	**.576**			.408
14	Worthless/*tidak bernilai*	**.532**	.531		
20	Not alive/*mati*	**.719**			
21	Miserable/*sengsara*	**.632**			.460
22	Discouraged/*tidak bersemangat*	**.638**	.327		.370
23	Lonely/*keseorangan*	**.767**			
24	Trapped/*terperangkap*	**.702**			.443
2	Good spirit/*semangat baik*	.354	**.687**		
3	Purposeless/*tidak bermakna*	.414	**.586**		
4	Role lost/*peranan hilang*	.387	**.633**		
5	Cope/*menghadapi*		**.726**		.305
7	Proud/*bangga*		**.608**		
1	Value/*nilai*			**.683**	
6	Role lost/*peranan hilang*			**.698**	
12	Helpless/*tiada bantuan*	.300		**.776**	
17	Accomplishment/*kejayaan*			**.710**	
19	Worthwhile/*berguna*		0.477	**.591**	
13	Regret/*penyesalan*		.433		**.530**
15	Hurt/*sakit hati*				**.854**
16	Angry/*marah*		.355		**.714**
18	Distressed/*tertekan*	.441		.345	**.557**

*Factors: 1=Disheartenment; 2=loss of meaning and purpose; 3=sense of failure; 4=Dysphoria.

5.4 *Reliability Testing*

Cronbach's alpha for DS-M's total score was .95 as shown in Table 6, which indicated a very high level of internal consistency. The Cronbach's alpha for each subscale were ranged from .81 to .92.

Table 7 presented the 'Cronbach's alpha if items deleted' in the final column. It showed the removal of any question, except question 1 (Q1) and 12 (Q12), had resulted in a poorer Cronbach's alpha. Removal of Q1 and Q12, however, had led to a small increment in Cronbach's alpha. Corrected item-total correlations for these two items were .39 for Q1 and .44 for Q12.

Table 3 described the intra-class correlation between each scale item from both original and Malay-translated version of DS. It revealed that the Cronbach's alpha for each item were more than 0.9. Besides, their intra-class correlations were also highly significant (*p* value <0.001).

Table 6: Internal Consistency (Cronbach's Alpha) of DS-M

		Alpha	Mean	SD
Total Scale		.947	18.79	15.30
Subscales	1: Disheartenment	.924	6.29	6.95
	2. Loss of meaning and purpose	.870	3.28	3.66
	3: Sense of failure	.805	5.40	4.01
	4: Dysphoria	.829	3.82	3.16

Abbreviation: SD=standard deviation

Table 7: Corrected-Item Total Correlation and Cronbach's Alpha if Items Deleted for DS-M

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
1	17.59	199.60	**.39**	.95
2	18.20	195.83	.69	.94
3	18.16	193.40	.71	.94
4	18.19	193.24	.73	.94
5	17.98	192.63	.68	.94
6	17.82	192.52	.55	.95
7	18.16	193.98	.65	.94
8	18.13	189.37	.69	.94
9	18.34	195.78	.66	.94
10	18.19	194.81	.62	.95
11	17.68	191.26	.66	.94
12	17.67	196.29	**.44**	.95
13	17.98	192.95	.59	.95
14	18.39	198.76	.69	.94
15	17.90	197.76	.56	.95
16	17.78	195.35	.67	.94
17	17.75	193.62	.55	.95
18	17.69	190.33	.72	.94
19	17.72	192.80	.58	.95
20	18.50	200.28	.65	.95
21	18.11	194.00	.74	.94
22	18.08	191.40	.78	.94
23	18.16	192.43	.71	.94
24	18.04	189.08	.74	.94

Abbreviation: DS-M=Malay version of Demoralisation Scale

5.5 Correlation between DS-M, DS, CESD, DT and PERS

Table 8 indicated significant positive correlations between DS-M with DS (r = 0.99), CESD (r = 0.78) and Distress Thermometer (r = 0.64). PERS had recorded negative associations with DS-M (-.69), DS (-.699), CES-D (-.67) and Distress Thermometer (-0.61).

Table 8: Spearman's Correlation (r) between DS-M and DS, CES-D, Distress Thermometer and PERS

	DS-M	DS	CES-D	DT	PERS
DS-M	1.00	.99	.78	.64	-.69
DS		1.00	.79	.64	-.70
CESD			1.00	.57	-.67
DT				1.00	-.61
PERS					1.00

** Correlation is significant at the 0.01 level (2-tailed).

Abbreviation: DS-M: Malay version of Demoralisation Scale; DS: original Demoralisation Scale (English version); CESD: Centre for Epidemiologic Studies Depression Scale; DT: Distress Thermometer; PERS: Positive Emotion Rating Scale.

5.6 Receiver Operating Characteristic (ROC) Curve

Figure 1 illustrated ROC curve of true positive rate (sensitivity) plotted in function of false positive rate (1-specificity). The area under the curve (AUC) was .92 (SE: .024, $p < 0.01$, 95% CI=0.88-0.97).

Snapshot of sensitivity and specificity of each score was illustrated in Table 9. The cut-off score of 23 was selected because of the balance between its sensitivity (.91) and specificity (.80). The positive predictive value (PPV) and negative predictive value (NPV) of the DS-M were .61 and .96 respectively.

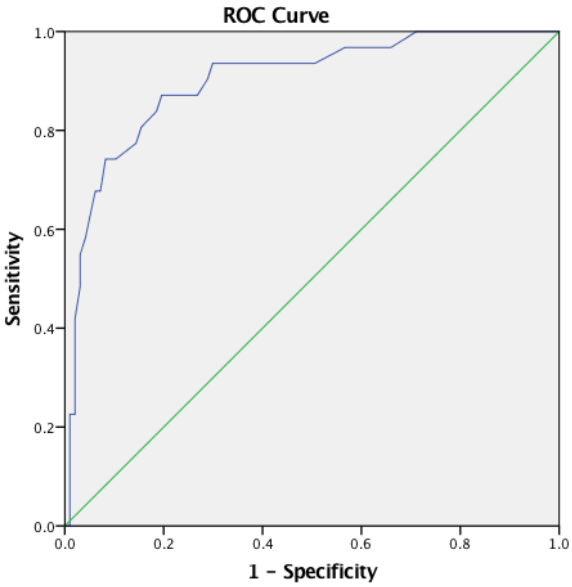


Figure 1: Receiver Operating Characteristic (ROC) Curve

Table 9: Sensitivity and Specificity of Each Coordinates for ROC Curve of DS-M

Score	Sensitivity	Specificity
20	.911	.727
21	.911	.750
22	.911	.795
23	**.911**	**.803**
24	.889	.818
25	.867	.856
27	.800	.864

Abbreviation: DS-M=Demoralisation Scale-Malay version

5.7 Associations with Sociodemographic and Clinical Characteristics

Univariate analysis of DS-M's total score with the cancer patients' sociodemographic characteristics showed no significant findings. The independent variables included sex, age, race, religion, marital status, number of children, educational level and employment status. The proportion of demoralised female or male patients were comparable, namely 36.8% and 39.1% respectively. There was no much difference as well for the two age groups (less than 45 versus 45 or more) in term of the percentage of demoralisation.

Interestingly, Malay and Muslim were less likely to be demoralised compared to their counterpart. In contrast to 42.1% in non-Malay cohort, only 31% of the Malay patients were shown to be demoralised. On the other hand, non-Muslim were prone to be demoralised (42.1%) in relative to the Muslim counterpart (30.1%).

In term of the proportion of demoralisation, those who were single or divorced did not significantly differ from those who were married. The percentage of demoralisation for both cohorts were 37.3 and 37.8 respectively. Similarly, number of children and educational level did not confer much difference in the fraction of demoralisation. Employed individuals had lower tendency to be demoralised in comparison with those who were not working (retirees, students, housewives etc.). While 41.4% of those who did not work were showed to be demoralised, there were only 30.6% of the employed subjects had clinically relevant level of demoralisation.

Table 10: Univariate Analysis of DS-M Score with Sociodemographic Characteristics of Patients with Cancer

Variables	DS-M Total Score, N (%)		Chi Square	Odd 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)				

Table 11 displayed the result of univariate analysis of the cancer patients' clinical characteristics with DS-M score. The dependent variables were low and high demoralisation groups. The independent variables included types and stages of cancer, duration since diagnosis, latest treatment, concomitant medical and psychiatric illnesses.

Types of cancer (breast cancer versus non-breast cancer) did not affect the level of demoralisation, as the portion of demoralised subjects were similar in both groups. They were 38.2% and 37.3 respectively. However, the proportion of demoralised subjects were slight higher in those with stage IV cancer (39.5%) and longer duration of diagnosis (38.4%). In the variable 'type of cancer treatment', the subjects who were having active cancer treatment such as radiotherapy and chemotherapy, tended to be more demoralised (39.3%) as compared to those who had no active cancer treatment. Again, Chi analysis had shown no significance of this relationship (x^2=.41, p=.52).

In this study, higher percentage of demoralised subjects were found in the groups without medical illnesses such as diabetes, hypertension or renal diseases. The proportions were 33% for the cohort with medical diseases and 67% for the group without medical illness. On the contrary, higher fraction of demoralised subjects were recorded in the group with prior history of psychiatric treatment (62.5%) as compared to that without (36.5%) (x^2=2.205, p=.14).

Table 11: Univariate Analysis of DS-M Score with Clinical Characteristics of Cancer Patients

Variables	DS-M Total Score, N (%)		Chi Square	Odd 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 12 described the univariate analysis of the total score of DS-M, CES-D, DT and PERS. 41 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). Majority, i.e. 96%, of those having low level of demoralisation were actually not depressed (n=110). The chi square was 72.76 (*p* value <0.01) and its odd ratio was 41.788 (95% CI=13.74-127.14).

Of the 67 persons in the cohort of 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 was 41.335 (p value <0.01) and its odd ration was .91 (95% CI=.04-.20).

For those having high degree of distress (DT ≥4), 66.7% were classified as having high demoralisation (n=46). Only twenty-seven 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 40.445 (p value <0.001) and its odd ratio was 8.38 (95% CI=4.20-16.72).

Table 12: Univariate Analysis of the Score of DS-M with CESD, PERS and DT

Variables	DS-M Total Score, N (%)		Chi Square	Odd 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.

5.8 Regression Analysis of the Associated Factors for DS-M

CESD, PERS and Distress scores were included into multiple logistic regression analysis. The result was shown in Table 13. For CESD, the standard error was .60 and the odd ratio was 3.13 with *p* value of <0.01. Besides, analysis of DT also revealed SE of 0.46 and odd ratio of 1.29 (*p* value <0.05). However, analysis of PERS showed insignificant result (*p* value >0.05). The odd ratio was -.93.

The model summary had indicated that 40.8% of the variation in the dependence variable is explained by the logistic model (Cox-and-Snell R^2=0.41). Nagelkerke R^2 value of 0.56 revealed a strong relationship between the predictors and prediction (DS-M).

Table 13: Multivariate Analysis of Associated Factors for DS-M

Scales	Standard Error (SE)	Odd Ratio (OR)	*p* Value
CESD	.60	3.13	<0.01
PERS	.56	-.93	0.10
DT	.46	1.29	<0.01

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

CHAPTER 6: DISCUSSION

6.1 Overview of the Study

This research was a cross-sectional study conducted in the ward and outpatient setting of Universiti Malaya Medical Centre (UMMC) from January to December 2017. This was the first study in Malaysia, examining the prevalence of demoralisation among the cancer patients in Malaysia. The correlation between demoralisation and positive emotion, depression and distress were explored. In addition, the association between demoralisation with sociodemographic, disease and treatment-related factors were evaluated. Apart from that, the study examined the psychometric properties of the Malay translated version of the Demoralisation Scale.

In this study, we found a significant association between the total score of the Demoralisation Scale and Positive Emotion Rating Scale, Centre for Epidemiologic Studies Depression Scale as well as Distress Thermometer. The study showed that the clinically relevant level of demoralisation was directly related to the depression and distress level. A negative association was found between demoralisation and positive emotion. On the other hand, no significant association was found between the level of demoralisation and the sociodemographic or the clinical properties.

The psychometric properties of DS-M were studied and the result was encouraging. DS-M demonstrated satisfactory psychometric properties when used as a tool to measure demoralisation among the subjects with cancer.

6.2 Overview of The Participants

Of the one hundred seventy-eight cancer patients who had been recruited into the study using the CESD, 25.3% of the subjects were identified to be depressed. Depression (CESD score $\geq$ 16) was more prevalent in males. One-third of the recruited male subjects were screened positive for depressive symptomatology. The prevalence of depression was lower in the females. Of the 114 females recruited, only 21% reported symptoms of depression.

Among the subjects, the Malay patients constituted two-fifths of the study population whereas the remaining three-fifths comprised of the non-Malay patients. The majority of the recruited subjects were married (71.3%) and they had an average of fewer than 2 children. A quarter of those participants were still single (24.7%).

Nearly all the subjects had achieved at least secondary education (44.4%). Close to one-third of them were working either part time or full time at the time of assessment. Of the remaining two-thirds, 43% was either retirees or pensioners.

6.3 Demoralisation among Cancer Patients

In the present study, the mean score for DS-M was 18.79 (SD=15.30). The result was similar to the findings in the different countries. 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. The scores were 23.90 (SD=14.50) and 29.8 (SD=10.41) (Costantini et al., 2013; A. Mehnert et al., 2011) respectively. Interestingly, in the original Australian study, the mean score was recorded as high as 43.1 (SD=23.20) (D.W. 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 the chronic illnesses.

In the present study, about 37.6% of the cancer patients were found to have a clinically relevant level of demoralisation by using DS-M. Robinson et al. (2015) had conducted a systemic review and reported a slightly lower prevalence of demoralisation, ranging from 13% to 18%. The prevalence of demoralisation varied with different diagnostic approaches. When the Diagnostic Criteria for Psychosomatic Research (DCPR) was used for evaluation, the prevalence of demoralisation was recorded as high as 33.3% (L. R. Grassi, E; Sabato, S; Cruciani, G; Zambelli, M;, 2004; D.W. Kissane et al., 2004; Nanni, Travado, Palma, Silvestrini, & Grassi, 2011; Robinson et al., 2015). Only those studies on patients with cancer were considered in reporting such prevalence.

It is noteworthy to mention that most of these prevalence studies were conducted in the Western countries. Only a few Asian researchers studied the prevalence of demoralisation in patients with cancer, and they reported relatively higher prevalence rates. Deng et al. (2017) and Lee et al. (2012) reported 47% and 49% of the patients with cancer were demoralised. Those studies were conducted in Mainland China and in Taiwan respectively. However, they did not explain the reason for the higher prevalence of demoralisation in their countries in comparison with the western studies.

Despite using the same screening tool (Demoralisation Scale), there was an evidently large disparity in the prevalence rate of demoralisation between the present and previous studies. It may be due to the differences caused by the different cultures, races, and countries. For example, Item 4 mentions ‘my role in life has been lost’. Markus and Kitayama (1991) reported that the Eastern society placed more emphasis on the interpersonal relatedness. In contrast to the western society, most of the elderlies in the Malaysian society stay with their children and help to care for their grandchildren. The diagnosis of cancer often brings about

changes of their roles in life. Instead of caring for their own children and grandchildren, they have become dependent after the diagnosis of the cancer.

The Westerners and Asians evaluate themselves differently based on the different life values. Living in a society that emphasizes more on family value, debilitating consequences of cancer resulted in a change in the self-esteem, and it affects the sense of self-worth, which are represented in Item 14 ('life is no longer worth living') and 19 ('I am a worthwhile person).

Frank (1974) reported that demoralisation was a result of the persistent failure of a person to cope with the internally or externally derived adversities. J.M. de Figueiredo (1993), and J. de Figueiredo, M. and Frank (1982) further described the state occurs when the individual perceives himself or herself as being incapable of dealing proficiently with a specific stressful situation. This is closely related to the general coping mechanism and personality of the Asian people. Self-suppression was taught since they were young (Abbott, 1970; Ting-Toomey, 1999). Asians have the tendency to be more introverted in relation to westerners because of the culture they live in (Fordham, 1956). The introverted characteristics include keeping to self, unsociable and over-conscientious. Moreover, the awareness towards psychiatric disorders is low, and the stigma related to the mental illness is considerably high in eastern society (C. G. Ng & Zainal, 2014). C. G. Ng and Zainal (2014) also found that most of the Asians did not fully understand and aware of cancer. As a result, the help-seeking behaviour is less likely in Asian society. Consequently, the cancer patients who experience existential distress and failure to cope tend to turn the negative emotion to themselves without seeking further help. This sociocultural difference could explain the higher prevalence of demoralisation in the Asian studies.

Apart from the aforementioned, different cut-off values were likely to contribute to the diverse prevalence rates. Most of the DS were using mean scores as the cut-off values to

differentiate between the high and low demoralisation levels. The values varied from 20 (Mullane et al., 2009) to 30 (A. Mehnert et al., 2011). However, D.W. Kissane et al. (2004) used the median score of 30 as the scale's cut-off point.

6.4 Depression among Cancer Patients

The present study identifies that approximately 25.3% of the patients with cancer are depressed as defined by the CESD (Table 4). The results were similar to the studies conducted on cancer patients in the other countries. The prevalence of depression among those patients varied from 9% (Celik et al., 2010), 20.7% (Mitchell et al., 2011; Wilson et al., 2007), 24% A. Mehnert et al. (2011) and 26.7% (Nikbakhsh et al., 2014). On the other hand, N. Z. Zainal et al. (2013) reviewed twelve Asian studies and found that the prevalence of depression could range from 3-39%.

The differences between the prevalence of depression in the studies were due to the methodological variations. Despite the methodological variations, it was well organised that certain types of cancers were associated with high occurrence of depression (Angelino & Treisman, 2001). The prevalence also varied between interview-based studies (Mitchell et al., 2011; Wilson et al., 2007) and those using different screening tools (Celik et al., 2010; Nikbakhsh et al., 2014). Several types of instrument used included Hamilton Depression Rating Scale, Beck Depression Inventory, and Centre for Epidemiologic Studies Depression (CES-D) Scale.

6.5 Differences between Demoralisation and Depression

Out of forty-five patients screened positive for depression with the CESD (score ≥16), about 89% were observed to have clinically relevant demoralisation state (chi square=72.755, p<0.001). This result was similar to the studies conducted in other countries. In the study done by A. Mehnert et al. (2011) in Germany, approximately 81% of the cancer subjects with depression had concurrent clinically relevant demoralisation. Similarly, D.W. Kissane et al. (2004) in an Australian study reported a percentage of 85% with demoralisation .

Depression and demoralisation are regarded as two distinct ontologies (D.W. Kissane, 2004; Robinson, Kissane, Brooker, & Burney, 2016). Twenty-six out of a total of 178 subjects (14.8%) in the present study were identified to achieve a higher score in the DS but were not clinically depressed. D.W. 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 cohort of patients should be considered differently.

A similar observation was found in several other studies (Costantini et al., 2013; Hung et al., 2010; A. Mehnert et al., 2011; Mullane et al., 2009). A. Mehnert et al. (2011) showed that about 5-20% of the subjects with advanced cancer were severely demoralised but were not clinically depressed, whereas 60% of the patients with moderate levels of demoralisation had no depression. Costantini et al. (2013) demonstrated that 6-20% of the patients were seriously demoralised but not clinically depressed. In addition, 16-31% of the study's patients had moderate levels of demoralisation but no clinical depression. In a study conducted in Portugal, Julião, Nunes, and Barbosa (2016) investigated 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.

Similarly, the topic of Demoralisation Scale had received much attention among the countries in Asia. The scale has gained the interest of the clinicians and researchers in China and Taiwan. Hung et al. (2010) who studied the validity of the Mandarin version of the scale (DS-MV), in an outpatient setting involving the patients with cancer at different stages of illness concluded that the DS-MV had acceptable reliability. Similar with previous studies, Hung et al. (2010) found that about a quarter of the study patients had lower rates of depression but a higher level of demoralisation. Deng et al. (2017) who examined the Mainland Chinese versions of the demoralisation scale (MC-DS), reported that 71% of the subjects had a medium level of demoralisation, and 15% had a high level of demoralisation state. In addition, Deng et al. (2017) found that close to 60% of the patients with a medium level of demoralisation were not depressed, whereas only 5% of patients with a high level of demoralisation were not depressed. Deng et al. (2017) concluded the MC-DS could detect mild-to-moderate demoralisation in the cancer patients but MC-DS at higher scores had poor specificity for demoralisation.

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. While those with higher levels of depression had higher scores on the components of loss of meaning, disheartenment, and sense of failure. Rudilla et al. (2016)'s study demonstrated that the demoralised palliative patients tended to be depressed. In a recently published systematic review paper 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, Wang, & Chou, 2015). Having said that, this syndrome is often unrecognised

in the ordinary medical treatment for cancer and this can be a risk factor for developing depression at a later stage (J. C. Jacobsen et al., 2006). These studies 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, as proposed by D.W. Kissane (2004).

The percentage of demoralisation in the previous studies had a wide range and could be due to the different cut-off points used. The scale categorized demoralisation scores into two (high and low) or three (high, medium and low) groups based on the mean score and standard deviation (Deng et al., 2017; L. Grassi et al., 2017; Robinson, Kissane, Brooker, Michael, et al., 2016). On the contrary, Mullane et al. (2009) found lower levels of demoralisation in their study compared with the study by D.W. Kissane (2004). Unlike what the other studies stated, Mullane et al. (2009) found that the subjects who attained higher demoralisation score had a significant inclination for higher scores for depressive symptoms. Therefore, the authors concluded that they could not support the divergent validity of demoralisation and depression.

In spite of the high association between demoralisation and depression, their clinical differences, as well as the management, could be very different. Demoralisation is organised as an urgent and potentially a treatable condition (D.W. Kissane et al., 2001). Evidence supports managing the mental health needs of these patients is a crucial part of the treatment process and may even impact prognosis (Robinson, Kissane, Brooker, & Burney, 2016). Thus, a fundamental distinction between demoralisation and depression must be made. On the one hand, the core features of depression are anhedonia and loss of interest in the usually pleasurable activities. Demoralisation, on the other hand, indicates helplessness and meaninglessness (Angelino & Treisman, 2001; J.M. de Figueiredo, 2007). The latter can be a normal psychological response to life events or stressors and may be without signifying a

brain pathology (Angelino & Treisman, 2001). The other main clinical characteristics associated with the demoralisation syndrome encompass social isolation, body disfigurement, chronic medical disorders and physical disability (D.W. Kissane et al., 2001; D.W. Kissane et al., 2004)

Scientists defined demoralisation as a state in which the individuals perceive themselves as being unable to cope with the current situation (D.W. Kissane et al., 2001; Vehling et al., 2017). Clinical demoralisation among the cancer patients is relevant as it commonly appears and is independent of mental disorders in the patients (D.M. Clarke & Kissane, 2002; M. J. Clarke, 2011). For the patients with cancer, the diagnosis, treatment, and rehabilitation are painful and distressing experiences (Vehling et al., 2012). The presence of demoralisation is associated with a sense of disheartenment and a loss of hope and meaning and has a unique contribution to feeling suicidal (D.M. Clarke & Kissane, 2002; D.W. Kissane et al., 2001; Vehling et al., 2017).

6.6 *Demoralisation and Positive Emotion in Cancer Patients*

To date, there is no evidence-based study conducted to assess the association between positive emotion and demoralisation. A quarter (25.3%) of the participants had lower level of positive emotion. Of these patients, nearly 77.8%, exhibited a low level of demoralisation (chi square=41.335, p value<0.001). Understandably, the higher the level of the positive emotion is, the lesser is the level of demoralisation. Nevertheless, the relationship can be deduced indirectly based on many previous evidence.

Research had shown that many of the mood disorders, including major depressive disorder, are associated with a specific level of deficiency in positive emotion (T. B. Brown, DH;, 2009; Gruber, 2011). Researchers concluded that individuals with depression have

difficulties in sustaining positive affectivity (Dichter & Tomarken, 2008; Dichter, Tomarken, Shelton, & Sutton, 2004; Kaviani et al., 2004). Additionally, in any depressive episode, there is often a sustained state of negative affect and a persistent reduction in positive affect (J. Joormann & Gotlib, 2010). When an individual is sad, the depression-vulnerable individual habitually suppresses his or her emotions and uses less of his or her reappraisal (Ehring et al., 2010; J. Joormann & Gotlib, 2010; Raes et al., 2014). The subsequent state is the continuation of the conflicting emotions either worsened or triggered by any unfavourable life events or on-going conflicts (Ehring et al., 2010). Raes et al. (2014) characterised a depressed individual as having an increase in the negative affect as well as the decrease in positive affect and a diminished ability to respond to the positive affect. Having positive emotions is vital to attaining essential goals, developing social attachments, and upholding cognitive flexibility (Gruber, 2011).

In the individuals with cancer, the diagnosis of cancer is a stressful event and having positive thinking is a vital attitude to cope with illness (Gilbert et al., 2016). Thus, having emotion regulation strategies can play an important role in the onset and maintenance of depression. The study supports the proposal of many authors to screen patients for symptoms of existential distress and depression to improve the detection and management of distress.

6.7 Demoralisation and Other Associated Factors

6.7.1 Sociodemographic factors

No relationship was found between demoralisation and the sociodemographic factors. The sociodemographic variables tested included age, race, religion, marital status,

educational level, income and so on.

Inconsistent results were reported on the relationship between age, gender and educational level. Some studies showed no association between age and demoralisation (Katz, Flasher, Cacciapaglia, & Nelson, 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 (A. Mehnert et al., 2011; Vehling, Oechsle, Koch, & Mehnert, 2013). Likewise, gender (L. Grassi, Sabato, Rossi, Biancosino, & Marmai, 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 findings in which demoralisation was higher in single patients who did not have any partner (Katz et al., 2001; A. 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 relationship.

6.7.2 Disease and Treatment-Related Factors

The current study did not show any significant association between the DS total score with clinical characteristics through the chi-square analysis. The clinical variables tested included type and stage of cancer, duration of diagnosis and concomitant medical or psychiatric illness and so on. These findings were consistent with the systemic review conducted by Robinson et al. (2015). This systemic review examined twenty-five relevant studies and concluded that there was no association between demoralisation and with most of the disease and treatment related factors. Three studies with over 700 participants had proven that the duration since the initial diagnosis was not associated with demoralisation (Boscaglia & Clarke, 2007; Katz et al., 2001; A. Mehnert et al., 2011). From the four studies with a total of 770 subjects, the stages of cancer were not associated with demoralisation (Boscaglia & Clarke, 2007; L. Grassi, Rossi, Sabato, Cruciani, & Zambelli, 2004; Lee et al., 2012; Vehling et al., 2012). In addition to that, Vehling et al. (2012), L. Grassi et al. (2004) and Lee et al. (2012) had also concluded the type of cancer treatment was not associated with demoralisation.

It is well-known that the stage of disease and time since diagnosis are directly related to cancer and its associated psychosocial consequences (Caruso, Nanni, Riba, Sabato, & Grassi, 2017). Theoretically, the patients with advanced cancer who suffer greatly from the metastasis and its treatment complications are deemed to experience 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, the present study 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 its suffers irrespective of the stage and treatment.

To date, there is no known relationship between the cancer site and demoralisation (Robinson et al., 2015). In a large study involving more than 500 German participants with advanced cancer, it was reported that there was no relationship between the site of cancer and demoralisation (A. Mehnert et al., 2011). Only scarce evidence indicated that certain type of tumours were related to higher demoralisation. Lee et al. (2012) had recruited over 200 subjects with heterogeneous cancers in Taiwan and revealed that head and neck cancer were more likely to be associated with demoralisation.

6.8 *The Psychometric Properties of the DS-M*

6.8.1 Construct Validity

The moderately strong positive association between these the scores of DT and DS-M indicated a considerable overlap between these two constructs, as the tools were intended to measure the similar negative emotion, i.e., psychological distress. Several researchers proposed the National Comprehensive Cancer Network (NCCN) Distress Thermometer as a widely-used screening tool to measure distress level among the cancer patients (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Roth et al., 1998). Similarly, the German adaptation study of the DS was the other study which used the Distress Thermometer (DT) in testing instrument's validity (A. Mehnert et al., 2011). The purpose for using the DT was that emotional distress was a common psychological occurrence in the people with cancer

(Carlson & Bultz, 2003; Massie, 2004; Monti, Mago, & Kunkel, 2005; Zailina, Yong, Zalilah, & Yong, 2011).

Depression and demoralisation are considered as two distinct entities (Angelino & Treisman, 2001; D.W. Kissane, 2004). The fundamental requirement for the validation of DS is the demonstration of the divergent ability between the constructs of depression and demoralisation (Angelino & Treisman, 2001; D.W. Kissane et al., 2004; Robinson, Kissane, Brooker, & Burney, 2016). In the present study, 14.6% of the subjects were demoralised without exhibiting depressive symptomatology clinically. D.W. Kissane et al. (2004) identified 7-14% of the patients who had a clinically relevant level of demoralisation but were not depressed. Hence, he concluded that there was the presence of a conceptual difference in both demoralisation and depression.

PERS is designed to measure positive emotion (C. G. Ng & Hazli, 2016) and is theoretically different from the DS-M, which measures the level of demoralisation. Through the quantitative hierarchical model, demoralisation and low positive emotion had been described as the essential conceptions of mood and anxiety disorder (Watson, 2005) and had correlated positively with each other (Sellbom, Ben-Porath, & Bagby, 2008). As expected, the DS-M had demonstrated a considerably strong discriminant construct validity in relation to PERS with a correlation coefficient of -0.694 (p-value < 0.01). Using the PERS in testing the divergent validity was a novel move.

6.8.2 Item-Total Correlation

The concerns were initially raised regarding the compatibility of Item 1 and 12 in the Malay-translated scale because of the improved Cronbach's Alpha if the items were deleted. Nonetheless, the two items remained in the instrument because of two reasons. Firstly, the improvement in Cronbach's alpha was only minimal and was not significant enough to warrant a drop from the total scale. Secondly, the corrected item-total correlations were 0.389 for item 1 and 0.440 for item 12. Corrected item-total correlation of more than 0.3 has provided sufficient evidence that both items virtually measured the same construct as measured by the other items in DS-M (Everitt, 2002; Field, 2005).

6.8.3 Factor Analysis

D.W. Kissane et al. (2004) proposed that the DS has 5-factor solutions. Indeed, most of the subsequent adaptions of DS suggested 5-factor structures with some variations (Hung et al., 2010; A. Mehnert et al., 2011; Mullane et al., 2009; Rudilla et al., 2016). However, none of them has successfully replicated the factor structures similar to how it was originally described. The current study extracted 4-factor solutions with some variations in the items in each dimension. The fourth factor, 'helplessness', as originally proposed by D.W. Kissane et al. (2004), was absent in the present study. Similarly, the German adaptation of DS also included only four dimensions without the factor 'helplessness' through the principal component factor analysis (Mullane et al., 2009). It is worthwhile to mention that D.W. Kissane et al. (2004) in his preliminary validation of DS, found that factor 'helplessness' obtained the lowest Cronbach's alpha (0.71) among the other four subscales. The observation may imply the inadequacy of the internal consistency that underlies this particular subscale early from the beginning.

6.8.4 Cut-Off Point

In the present study, the optimal decision threshold value of 23 was chosen when both the sensitivity and specificity were taken into account. In contrast, the other adaptation studies had used different methods to calculate the cut-off value. D.W. Kissane et al. (2004) used a median score (30.82) to determine the high and low demoralisation groups. However, D.W. Kissane et al. (2004) did not present any rationale to why the use of the median cut-off value. The subsequent adaptation papers used the mean a $\pm$ 1 standard deviation as the appropriate cut-off point (A. Mehnert et al., 2011; Rudilla et al., 2016).

CHAPTER 7: LIMITATIONS, STRENGTH, AND RECOMMENDATION

7.1 Limitation of This Study

There were several limitations in the study. First and foremost, the study population was limited to patients with cancer who were present in UMMC. Hence, the generalizability of the study findings is limited and may not be applicable to the other fields of medicine such as end-stage renal or heart diseases. The use of this Malay-translated version of Demoralisation Scale is only tested in the cancer population.

Secondly, the convenient sampling method used may contribute to a higher risk of selection bias. Subjectivity in the selection process can make it difficult to measure changes across places and time. Additionally, the sampling was limited to only one centre, UMMC; its patients may be characteristically different from that of the rest of Malaysia. UMMC is located in a strategic area in Kuala Lumpur. Kuala Lumpur is the capital of Malaysia and it is an urban area in which many of the population have a higher educational level. Hence, the response to the questionnaire could be instinctively different.

The oncology clinic has a few hundred patients. Given the crowded setting, the patients could have anxiety and this feeling could affect the accuracy in answering the questionnaires. They could be answering the questions swiftly without comprehending them in depth. In addition, the setting could have resulted in them being less willing to endorse the negative symptoms on the scales. Fatigability in answering a long list of questionnaires could be another detrimental factor in obtaining a true effect. All of these are virtually the issues of self-reporting questionnaires. Therefore, response bias could be present.

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.

7.2 Strength of the Study

This was the first study measuring demoralisation in the local clinical setting. Lack of concern about the presence of demoralisation among the cancer patients could possibly affect the treatment process and various complications such as depression and suicide may ensue. This study had recorded some encouraging results to inspire more research in the future.

Most of the patients in UMMC were at least bilingual and can perform equally well in both Malay and English versions of Demoralisation Scale. The author had taken the chance to translate and validate the DS-M at the same time. The Malay Language is the national language, and most of the Malaysians generally have a higher proficiency of the Malay language. Assessing demoralisation in the Malay language might potentially reduce the language bias resulting from the original English version.

This study adopted the newly-created Positive Emotion Rating Scale (PERS) to investigate the divergent validity of DS-M. PERS was a validated scale to examine the positive emotion in the general population. Using PERS was novel because none of the previous studies had used PERS before. Most of the previous studies used depression or anxiety for the study of discriminative validity.

In addition, the face and construct validities had been taken into consideration while validating this Malay-translated instrument. This had further strengthened and proven the psychometric properties of DS-M.

7.3 Recommendation

Increasing the sample size of the study can introduce a more significant benefit. The accuracy of the measurement depends on the extent to which the systemic error can take place. Minimizing the systemic error by increasing the sample size can consequently increase the accuracy of the instrument in measuring the construct it intends to measure. The significance of the study may be affected due to sample inadequacy.

Sampling method should be improved. Probability sampling methods include simple random sampling, stratified sampling, and cluster sampling. By employing this scientific method of collecting samples, the result will be less biased, more objective and representative.

More psycho-social background of the patients should be included and analysed in the future studies on demoralisation, as they are likely to contribute to the state of demoralisation. The suggested variables include coping mechanism, religious coping, and physical symptoms. Suicidality as one of the important element related to, should be included in the future study.

Besides, a multicentre study should also be considered as the samples from a single centre do not represent the average characteristics of Malaysians. The Malaysians from the different geographical areas vary significantly in many aspects such as culture, language, and religious coping. These differences will affect the presentation of demoralisation considerably.

As this is a cross-sectional study designed to examine the prevalence of demoralisation, additional confirmatory validation of DS-M should be performed in other diverse populations such as the people in Sabah and Sarawak. These strategies can further expand the representativeness of DS-M. More factor analytical studies are required to fully validate the Demoralisation Scale, as none of the presently available research has successfully replicated the original factor structures.

CHAPTER 8: CONCLUSION

The existence of demoralisation faced by the patients with cancer has received increasing interest in research internationally. This is the first study in Malaysia examining the demoralisation and its associated factors among cancer patients in Malaysia. The high prevalence of demoralisation (37.6%) in the local cancer population is indeed an alarming sign to the oncology team and mental health workers. With the ease of accessible psychiatric consultation in most of the general hospitals with oncology service, screening for demoralisation should be routinely done. Identifying the subset of patients with high demoralisation who are clinically not 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. Considering the diverse social and clinical characteristics, an appropriate biopsychosocial approach should be attempted when the individuals with cancer are identified to be demoralised. A careful management of the condition has the potential to ultimately increase the quality of life of the individuals with terminal illness.

The study proceeded to translate and validate the Malay version of the Demoralisation Scale, and to seek its reliability and relevance as an instrument used in the local setting. The study showed that the DS-M was a valid and reliable instrument to evaluate demoralisation syndrome in patients with cancer. The optimal cut-off value is 23 after considering both of the sensitivity and specificity. The area under the curve is 0.90 with a high significance level and narrow confidence interval. The convergent and divergent construct validities are also tested to be adequate.

CHAPTER 9:

REFERENCES

Abbott, K. A. (1970). *Harmony and individualism*. Taipei: Oriental Cultural Service.

Adler, N. E., Page, A. E., & Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. (2008). The psychosocial needs of cancer patients *Cancer care for the whole patient: Meeting psychosocial health needs*. Washington (DC): National Academies Press (US).

American Cancer Society. (2012). Cancer facts and Figures 2012. Retrieved from http://www.cancer.org/

American Institute for Cancer Research. (2012). *Food, nutrition, physical activity and the prevention of cancer: A global perspective* (Vol. 2007). Washington, DW: AICR.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5)*. Arlington: American Psychiatric Publishing.

Anand, P., Kunnumakkara, A. B., Sundaram, C., Harikumar, K. B., Tharakan, S. T., Lai, O. S., . . . Aggarwal, B. B. (2008). Cancer is a preventable disease that requires major lifestyle changes. *Pharm Res, 25*(9), 2097-2116. doi:10.1007/s11095-008-9661-9

Angelino, A. F., & Treisman, G. J. (2001). Major depression and demoralization in cancer patients: diagnostic and treatment considerations. *Support Care Cancer, 9*, 344-349.

Arran, N., Craufurd, D., & Simpson, J. (2014). Illness perceptions, coping styles and psychological distress in adults with Huntington's disease. *Psychology, Health and Medicine, 19*(2), 169-179. doi:10.1080/13548506.2013.802355

Ashby, F. G., & Isen, A. M. (1999). A neuropsychological theory of positive affect and its influence on cognition. *Psychological Review, 106*(3), 529-550.

Asma, S., Mackay, J., Song, S. Y., Zhao, L., Morton, J., & Palipudi, K. M. (2015). *The Global Adult Tobacco Survey Atlas*. Retrieved from Atlanta, GA:

Aspinwall, L. G., & Tedeschi, R. G. (2010). The value of positive psychology for health psychology: Progress and pitfalls in examining the relation of positive phenomena to health. *Annals of Behavioral Medicine, 39*(1), 4-15.

Azizah, A. M., Nor Saleha, I. T., Noor Hashimah, A., Asmah, Z. A., & Mastulu, W. (2016). *Malaysian National Cancer Registry Report 2007-2011: Malaysia Cancer Statistic, Data and Figure* (MOH/P/IKN/01.16 (AR)). Retrieved from Malaysia:

Bagge, C. L., Lamis, D. A., Nadorff, M., & Osman, A. (2014). Relations between hopelessness, depressive symptoms and suicidality: mediation by reasons for living. *Journal of Clinical Psychology, 70*(1), 18-31. doi:10.1002/jclp.22005

Bailey, R. K., Geyen, D. J., Scott-Gurnell, K., Hipolito, M. M. S., Bailey, T. A., & Beal, J. M. (2005). Understanding and treating depression among cancer patients. *International Journal of Gynecological Cancer, 15*, 203–208. doi:10.1111/j.1525-1438.2005.15204.x

Bardwell, W. A., & Fiorentino, L. (2012). Risk factors for depression in breast cancer survivors: An update. . *International Journal of Clinical and Health Psychology, 12*, 311-331.

Batty, G. D., Russ, T. C., Stamatakis, E., & Kivimaki, M. (2017). Psychological distress in relation to site specific cancer mortality: pooling of unpublished data from 16 prospective cohort studies. *BMJ, 356*, j108. doi:10.1136/bmj.j108

Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine (Phila Pa 1976), 25*(24), 3186-3191.

Berry, D. L., Blonquist, T. M., Hong, F., Halpenny, B., & Partridge, A. H. (2015). Self-reported adherence to oral cancer therapy: relationships with symptom distress, depression, and personal characteristics. *Patient Prefer Adherence, 9*, 1587-1592. doi:10.2147/PPA.S91534

Bornbaum, C. C., Fung, K., Franklin, J. H., Nichols, A., Yoo, J., & Doyle, P. C. (2012). A descriptive analysis of the relationship between quality of life and distress in individuals with head and neck cancer. *Supportive Care in Cancer, 20*, 2157-2165. . doi:http://dx.doi.org/10.1007/s00520-011-1326-2

Boscaglia, N., & Clarke, D. M. (2007). Sense of coherence as a protective factor for demoralisation in women with a recent diagnosis of gynaecological cancer. *Psychooncology, 16*, 189-195.

Bray, F., Shield, K. D., & i-Han, L. (2008). Cancer: Global burden, trends, and projections. *International Encyclopedia of Public Health, Second Edition*, 347-368. doi:10.1016/B978-012373960-5.00265-3

Brown, T. A. (2007). Temporal course and structural relationships among dimensions of temperament and DSM-IV anxiety and mood disorder constructs. *Journal of Abnormal Psychology, 116*(2), 313-328. doi:10.1037/0021-843X.116.2.313

Brown, T. B., DH;. (2009). A Proposal for a Dimensional Classification System Based on the Shared Features of the DSM-IV Anxiety and Mood Disorders: Implications for Assessment and Treatment. *Psychological Assessment, 21*(3), 256-271. doi:10.1037/a0016608

Campbell-Sills, L., Barlow, D. H., Brown, T. A., & Hofmann, S. G. (2006a). Acceptability and suppression of negative emotion in anxiety and mood disorders. *Emotion, 6*(4), 587-595.

Campbell-Sills, L., Barlow, D. H., Brown, T. A., & Hofmann, S. G. (2006b). Effects of suppression and acceptance on emotional responses of individuals with anxiety and mood disorders. *Behaviour Research and Therapy, 44*(9), 1251-1263.

Campos, R. C., Holden, R. R., Laranjeira, P., Troister, T., & Oliveira, A. R. (2016). Self-report depressive symptoms do not directly predict suicidality in nonclinical individuals: Contributions toward a more psychosocial approach to suicide risk. *Journal of Death Studies, 40*(6), 335-349. doi:dx.doi.org/10.1080/07481187.2016.1150920

Carl, J. R., Soskin, D. P., Kerns, C., & Barlow, D. H. (2013). Positive emotion regulation in emotional disorders: A theoretical review. *Clinical Psychology Review, 33*(3), 343-360.

Carlson, L. E., & Bultz, B. D. (2003). Cancer distress screening. Needs, models, and methods. *Journal of Psychosomatic Research, 55*(5), 403-409.

Caruso, R., Nanni, M. G., Riba, M. B., Sabato, S., & Grassi, L. (2017). The burden of psychosocial morbidity related to cancer: patient and family issues. *International Review of Psychiatry, 29*(5), 389-402. doi:10.1080/09540261.2017.1288090

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., . . . Clark, K. C. (1993). How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *Journal of Personality and Social Psychology, 65*(2), 375-390.

Carver, C. S., Smith, R. G., Antoni, M. H., Petronis, V. M., & Derhagopian, R. P. (2005). Optimistic personality and psychosocial well-being during treatment predict psychosocial well-being among long-term survivors of breast cancer. *Health Psychology, 24*, 508-516.

Casellas-Grau, A., Vives, J., Font, A., & Ochoa, C. (2016). Positive psychological functioning in breast cancer: An integrative review. *The Breast, 27*, 136-168.

Celik, O., Gorken, I., & Sahin, S. (2010). Depression and anxiety levels in woman under follow-up for breast cancer: relationship to coping with cancer and quality of life. *Medical Oncology, 27*, 108-113. doi:10.1007/s12032-009-9181-4

Chen, W., Zheng, R., Baade, P. D., Zhang, S., Zeng, H., Bray, F., . . . He, J. (2016). Cancer statistics in China, 2015. *CA: A Cancer Journal for Clinicians, 66*, 115–132. doi:doi:10.3322/caac.21338

Chida, Y., Hamer, M., & Molloy, G. J. (2009). Psychological distress and cancer mortality. *Journal of Psychosomatic Research, 66*(3), 255–258.

Chida, Y., Hamer, M., Wardle, J., & Steptoe, A. (2008). Do stress-related psychosocial factors contribute to cancer incidence and survival? . *Nature Clinical Practice Oncology, 5*(8), 466-476.

Clarke, D. M., Cook, K. E., & Coleman, K. (2006). A qualitative examination of the experience of 'depression' in hospitalized medically ill patients. *Psychopathology, 39*, 303-312.

Clarke, D. M., & Kissane, D. W. (2002). Demoralization: Its phenomenology and importance. *Australian and New Zealand Journal of Psychiatry, 36*(6), 733-742.

Clarke, D. M., Kissane, D. W., Trauer, T., & Smith, G. C. (2005). Demoralization, anhedonia and grief in patients with severe physical illness. *World Psychiatry, 4*(2), 96-105.

Clarke, D. M., Mackinnon, A. J., Smith, G. C., McKenzie, D. P., & Herrman, H. E. (2000). Dimensions of psychopathology in the medically ill. A latent trait analysis. *Psychosomatics, 41*(5), 418-425. doi:10.1176/appi.psy.41.5.418

Clarke, D. M., Piterman, L., Byrne, C. J., & Austin, D. W. (2008). Somatic symptoms, hypochondriasis and psychological distress: a study of somatisation in Australian general practice. *Med J Aust, 189*(10), 560-564.

Clarke, D. M., Smith, G. C., Dowe, D. L., & McKenzie, D. P. (2003). An empirically derived taxonomy of common distress syndromes in the medically ill. *Journal of Psychosomatic Research, 54*(4), 323-330.

Clarke, L., Ungerer, J., Chahoud, K., Johnson, S., & Stiefel, I. (2002). Attention deficit hyperactivity disorder is associated with attachment insecurity. *Clinical Child Psychology and Psychiatry, 7*(2), 179-198.

Clarke, M. J. (2011). *Discrimination between depression and demoralization in hospitalized adult bone marrow transplant patients* (Doctor Of Philosophy In Psychology), Fielding Graduate University Retrieved from http://ezproxy.um.edu.my:2048/login?url=https://search.proquest.com/docview/915643542?accountid=28930 Available from ProQuest Dissertations & Theses Global

Cohn, M. A., & Fredrickson, B. L. (2010). In search of durable positive psychology interventions: Predictors and consequences of long-term positive behavior change. *The Journal of Positive Psychology, 5*(5), 355-366.

Compas, B. E., & Luecken, L. (2002). Psychological adjustment to breast cancer. *Current Directions in Psychological Science, 11*(3), 111-114.

Compas, B. E., Stoll, M. F., Thomsen, A. H., Oppedisano, G., Epping‐Jordan, J. E., & Krag, D. N. (1999). Adjustment to breast cancer: age‐related differences in coping and emotional distress. *Breast cancer research and treatment, 54*(3), 195-203.

Costantini, A., Picardi, A., Brunetti, S., Trabucchi, G., Bersani, F. S., Minichino, A., & Marchetti, P. (2013). Italian version of Demoralization Scale: a validation study. *Rivista di Psichiatria, 48*(3), 234-239.

Daniel, W. W. (1999). *Biostatistics: A Foundation for Analysis in the Health Sciences* (t. edition Ed.). New York: John Wiley & Sons.

de Figueiredo, J., M. , & Frank, J. D. (1982). Subjective incompetence, the clinical hallmark of demoralization. *Comprehensive Psychiatry, 23*, 353-363.

de Figueiredo, J. M. (1993). Depression and demoralization: Phenomenologic differences and research perspectives. *Comprehensive Psychiatry, 34*(5), 308-311.

de Figueiredo, J. M. (2007). Demoralization and psychotherapy: A tribute to Jerome D. Frank, MD, PhD (1909-2005). *Psychotherapy and Psychosomatics, 76*(3), 129-133.

de Figueiredo, J. M., & Griffith, J. L. (2016). Chronic pain, chronic demoralization, and the role of psychotherapy. *Journal of Contemporary Psychotherapy, 46*(3), 167-177.

de Souza, B. F., de Moraes, J. A., Inocenti, A., dos Santos, M. A., Silva, A. E., & Miasso, A. I. (2014). Women with breast cancer taking chemotherapy: depression symptoms and treatment adherence. *Rev Lat Am Enfermagem, 22*(5), 866-873.

Decat Bergerot, C., & Cavalcanti Ferreira de Araujo, T. C. (2014). Assessment of distress and quality of life of cancer patients over the course of chemotherapy. *Investigacion Y Educacion En Enfermeria, 32*(2), 216-224. doi:10.1590/S0120-53072014000200004

Decat, C. S., de Araujo, T. C., & Stiles, J. (2011). Distress levels in patients undergoing chemotherapy in Brazil. *Psychooncology, 20*(10), 1130-1133. doi:10.1002/pon.1833

Deng, L., Pang, Y., He, Y., Zhang, Y., Fielding, R., & Tang, L. (2017). Demoralization among cancer patients in mainland China: validity of the Demoralization Scale (DS). *bioRxiv 144865*. doi:10.1101/144865

Department of Statistics Malaysia. (2017). Statistics on Causes of Death, Malaysia, 2017 [Press release]. Retrieved from https://www.dosm.gov.my/v1/index.php?r=column/pdfPrev&id=Y3psYUI2VjU0ZzRhZU1kcVFMMThGUT09

Derogatis, L. R., & Morrow, G. R. (1983). The Prevalence of Psychiatric Disorders Among Cancer Patients. *The Journal of the American Medical Association, 249*(6), 751-757.

Dichter, G. S., & Tomarken, A. J. (2008). The chronometry of affective startle modulation in unipolar depression. *Journal of Abnormal Psychology, 117*(1), 1-15. doi:10.1037/0021-843X.117.1.1

Dichter, G. S., Tomarken, A. J., Shelton, R. C., & Sutton, S. K. (2004). Early- and late-onset startle modulation in unipolar depression. *Psychophysiology, 41*(3), 433-440. doi:10.1111/j.1469-8986.00162.x

Diener, E. (1999). Introduction to the special section on the structure of emotion. *Journal of Personality and Social Psychology, 76*, 803–804.

DiMatteo, M. R., & Haskard-Zolnierek, K. B. (2010). Impact of Depression on Treatment Adherence and Survival from Cancer. In D. Kissane, M. Maj, & N. N. Sartorius (Eds.), *Depression and Cancer*. Chichester, UK: John Wiley & Sons, Ltd.

Duijts, S. F., van Egmond, M. P., Spelten, E., van Muijen, P., Anema, J. R., & van der Beek, A. J. (2014). Physical and psychosocial problems in cancer survivors beyond return to work: a systematic review. *Psychooncology, 23*(5), 481-492. doi:10.1002/pon.3467

Dunkel-Schetter, C., Feinstein, L. G., Taylor, S. E., & Falke, R. L. (1992). Patterns of coping with cancer. *Health Psychology, 11*(2), 79-87.

Dunlop, B. W., & Nemeroff, C. B. (2007). The role of dopamine in the pathophysiology of depression. *Arch Gen Psychiatry, 64*(3), 327-337. doi:10.1001/archpsyc.64.3.327

Dunn, B. D. (2012). Helping depressed clients reconnect to positive emotion experience: Current insights and future directions. *Clinical Psychology and Psychotherapy, 19*(4), 326-340.

Ehring, T., Fischer, S., Schnülle, J., Bösterling, A., & Tuschen-Caffier, B. (2008). Characteristics of emotion regulation in recovered depressed versus never depressed individuals. *Personality and Individual Differences, 44*(7), 1574-1584.

Ehring, T., Tuschen-Caffier, B., Schnülle, J., Fischer, S., & Gross, J. J. (2010). Emotion regulation and vulnerability to depression: Spontaneous versus instructed use of emotion suppression and reappraisal. *Emotion, 10*(4), 563-572.

Ellsworth, P. C., & Smith, C. A. (1988). Shades of joy: Patterns of appraisal differentiating pleasant emotions. *Cognition and Emotion, 2*, 301–331.

Endicott, J. (1983). Measurement of depression patients with cancer. *Cancer, 53*, 2243-2248.

Engel, G. L. (1967). A psychological setting of somatic disease: the 'giving up—given up'complex.

EPEC, I. f. E. a. t. A. M. A. (2000). *Education for Physicians on End-of-life Care*. Chicago, IL: American Medical Association.

Epping-Jordan, J. E., Compas, B. E., Osowiecki, D. M., Oppedisano, G., Gerhardt, C., Primo, K., & Krag, D. N. (1999). Psychological adjustment in breast cancer: Processes of emotional distress. *Health Psychology, 18*, 315-326.

Epstein, R. M., & Borrell-Carrio, F. (2005). The biopsychosocial model: Exploring six impossible things. *Families, Systems, and Health, 23*(4), 426-431. doi:10.1037/1091-7527.23.4.426.

Everitt, B. S. (2002). *The Cambridge Dictionary of Statistics* (Second ed.): Cambridge University Press.

Fang, C. K., Chang, M. C., Chen, P. J., Lin, C. C., Chen, G. S., Lin, J., . . . Li, Y. C. (2014). A correlational study of suicidal ideation with psychological distress, depression, and demoralization in patients with cancer. *Support Care Cancer, 22*(12), 3165-3174. doi:10.1007/s00520-014-2290-4

Fava, G. A., Freyberger, H. J., & Bech, P. (1995). Diagnostic criteria for use in psychosomatic research. *Psychotherapy and Psychosomatics, 63*(1), 1-8. doi:10.1159/000288931

Feldman, G. C., Joormann, J., & Johnson, S. L. (2008). Responses to positive affect: A self-report measure of rumination and dampening. *Cognitive Therapy and Research, 32*(4), 507-525.

Ferlay, J., Soerjomataram, I., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., . . . Bray, F. (2015). Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012. *International Journal of Cancer, 136*, E359–E386. doi:doi:10.1002/ijc.29210

Field, A. (2005). *Discovering Statistics Using SPSS*: Sage Publications Ltd.

Fordham, F. (1956). *An introduction to Jung's psychology*: Richard Clay & Company.

Frank, J. D. (1974). Psychotherapy: The Restoration of Morale. *The American Journal of Psychiatry, 131*, 271-274.

Frankl, V. E. (1973). The doctor and the soul: From psychotherapy to logotherapy *The doctor and the soul*. New York: Vintage Books.

Fredrickson, B. L. (1998). What good are positive emotions? *Review of General Psychology, 2*(3), 300-319.

Fredrickson, B. L. (2001). The role of positive emotions in positive psychology. *American Psychology, 56*(3), 218–226.

Fredrickson, B. L., & Joiner, T. (2002). Positive emotions trigger upward spirals toward emotional well-being. *Psychological Science, 13*(2), 172-175.

Fredrickson, B. L., & Losada, M. F. (2005). Positive affect and the complex dynamics of human flourishing. *American Psychologist, 60*(7), 678-686.

Gilbert, É., Savard, J., Gagnon, P., Savard, M. H., Ivers, H., & Foldes-Busque, G. (2016). To be or not to be positive: Development of a tool to assess the relationship of negative, positive, and realistic thinking with psychological distress in breast cancer. *Journal of Health Psychology*, 1359. doi:105316681062

Gogou, P., Tsilika, E., Parpa, E., Kouvaris, I., Damigos, D., Balafouta, M., . . . Mystakidou, K. (2015). The impact of radiotherapy on symptoms, anxiety and QoL in patients with cancer. *Anticancer Res, 35*(3), 1771-1775.

Goh, S. A., Steele, J. R., Jones, S. C., & Munro, B. J. (2013). Self-reported side effects of breast cancer treatment: A cross-sectional study of incidence, associations, and the influence of exercise. *Cancer Causes and Control, 24*, 517-528.

Grassi, L., Costantini, A., Kissane, D., Brunetti, S., Caruso, R., Piazza, G., . . . Nanni, M. G. (2017). The factor structure and use of the Demoralization Scale (DS‐IT) in Italian cancer patients. *Psycho‐Oncology, 26*(11), 1965–1971. doi:10.1002/pon.4413

Grassi, L., & Nanni, M. G. (2016). Demoralization syndrome: New insights in psychosocial cancer care. *Cancer, 122*(14), 2130-2133.

Grassi, L., Rossi, E., Sabato, S., Cruciani, G., & Zambelli, M. (2004). Diagnostic criteria for psychosomatic research and psychosocial variables in breast cancer patients. *Psychosomatics, 45*(6), 483-491. doi:10.1176/appi.psy.45.6.483

Grassi, L., Sabato, S., Rossi, E., Biancosino, B., & Marmai, L. (2005). Use of the diagnostic criteria for psychosomatic research in oncology. *Psychother Psychosom, 74*(2), 100-107. doi:10.1159/000083168

Grassi, L. R., E; Sabato, S; Cruciani, G; Zambelli, M;. (2004). Diagnostic criteria for psychosomatic research and psychosocial variables in breast cancer patients. *Psychosomatics, 45*, 483-491.

Greene, T. R., & Noice, H. (1988). Influence of positive affect upon creative thinking and problem solving in children. *Psychological Reports, 63*(3), 895-898.

Gross, A. F., Smith, F. A., & Stern, T. A. (2007). Is Depression an Appropriate Response to Having Cancer? A Discussion of Diagnostic Criteria and Treatment Decisions. *Primary Care Companion to The Journal of Clinical Psychiatry, 9*(5), 382–387.

Gross, J. J. (1998). The emerging field of emotion regulation: An integrative review. *Review of General Psychology 2*(3), 271-299.

Gross, J. J. (2002). Emotion regulation: Affective, cognitive, and social consequences. *Psychophysiology, 39*(3), 281-291.

Grotmol, K. S., Lie, H. C., Hjermstad, M. J., Aass, N., Currow, D., Kaasa, S., . . . European Palliative Care Research Collaborative, E. (2017). Depression-a major contributor to poor quality of life in patients with advanced cancer. *Journal of Pain and Symptom Management.* doi:10.1016/j.jpainsymman.2017.04.010

Gruber, J. (2011). Can feeling good can be bad? Positive emotion persistence (PEP) in bipolar disorder. *Current Directions in Psychological Science, 20*, 217-221.

Guan, N. C., Zakaria, H., Ghaus, Z., Gani, F. A., Zain, A., Choong, A. Y. K., & Ping, L. P. (2016). Development and validation of the Positive Emotion Rating Scale (PERS). *International Journal of Academic Research, 8*.

Hadnagy, Z., Csikós, Á., & Nagy, L. (2012). Introduction of the demoralization scale in Hungary, a study on demoralization and depression among hospice patients. *Orvosi Hetilap, 153*(19), 737-743.

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*(2), 141-184.

Hamer, M., Chida, Y., & Molloy, G. J. (2009). Psychological distress and cancer mortality. *Journal of Psychosomatic Research, 66*(3), 255-258. doi:10.1016/j.jpsychores.2008.11.002

Helgeson, V. S., Snyder, P., & Seltman, H. (2004). Psychological and physical adjustment to breast cancer over 4 years: Identifying distinct trajectories of change. *Health Psychology, 23*(1), 3-5.

Hickie, I. (2007). Is depression overdiagnosed? No. *British Medical Journal, 335*(7615), 329. doi:10.1136/bmj.39268.497350.AD

Hisham, A. N., & Yip, C. H. (2004). Overview of breast cancer in Malaysian women: A problem with late diagnosis. *Asian Journal of Surgery, 27*(2), 130-133.

Hoffman, B. M., Zevon, M. A., D'Arrigo, M. C., & Cecchini, T. B. (2004). Screening for distress in cancer patients: The NCCN rapid‐screening measure. *Psycho‐Oncology, 13*(11), 792-799.

Hopman, P., & Rijken, M. (2015). Illness perceptions of cancer patients: relationships with illness characteristics and coping. *Psychooncology, 24*(1), 11-18. doi:10.1002/pon.3591

Howard-Anderson, J., Ganz, P. A., Bower, J. E., & Stanton, A. L. (2012). Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: a systematic review. *Journal of the National Cancer Institute, 104*(5), 386-405. doi:10.1093/jnci/djr541

Hung, H. C., Chen, H. W., Chang, Y. F., Yang, Y. C., Liu, C. L., Hsieh, R. K., . . . Liu, S. I. (2010). Evaluation of the reliability and validity of the Mandarin Version of Demoralization Scale for cancer patients. *Journal of Internal Medicine Taiwan, 21*(6), 427-435.

Hunter, W. M., Cox, C. E., Teagle, S., Johnson, R. M., Mathew, R., Knight, E. D., & Leeb, R. T. (2003). Measures for assessment of functioning and outcomes in longitudinal research on child abuse. *Early Childhood.* Retrieved from http://www.iprc.unc.edu/longscan/

Hunter, W. M., Cox, C. E., Teagle, S., Johnson, R. M., Mathew, R., Knight, E. D., & Leeb, R. T. (2003). *Measures for Assessment of Functioning and Outcomes in Longitudinal Research on Child Abuse. Volume 2: Middle Childhood.* : LONGSCAN.

Institute for Health Matrics and Evaluation. (2016). Malaysia: What health problems cause the most disability? , from University of Washinton http://www.healthdata.org/malaysia

Institute for Public Health (IPH). (2012). *Report of the Global Adult Tobacco Survey (GATS) Malaysia 2011*. Retrieved from http://www.who.int/tobacco/surveillance/survey/gats/malaysia_country_report_2011.pdf

Institute for Public Health (IPH). (2015). *The National Health & Morbidity Survey (NHMS) 2015: Non-Communicable Diseases, Risk Factors and Other Health Problems*. Retrieved from Kuala Lumpur, Malaysia:

Institute of Medicine (US) Committee on Cancer Control. (2007). The cancer burden in low- and middle-income countries and how it is measured. In F. A. Sloan & H. Gelband (Eds.), *Cancer control opportunities in low- and middle-income countries*. Washington (DC): National Academies Press (US).

International Agency for Research on Cancer. (2013). Latest world cancer statistics [Press release]

International Agency for Research on Cancer, WHO. (2012). GLOBOCAN 2012: Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012. Retrieved from http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx

Irwin, S. A., & Ferris, F. D. (2008). The opportunity for psychiatry in palliative care. *Can J Psychiatry, 53*(11), 713-724. doi:10.1177/070674370805301103

Isen, A. M., Daubman, K. A., & Nowicki, G. P. (1987). Positive affect facilitates creative problem solving. *Journal of Personality and Social Psychology, 52*, 1122–1131.

Isen, A. M., Niedenthal, P., & Cantor, N. (1992). The influence of positive affect on social categorization. *Motivation and Emotion, 16*, 65–78.

Jacobsen, J. C., Maytal, G., & Stern, T. A. (2007). Demoralization in medical practice. *Primary Care Companion to the Journal of Clinical Psychiatry, 9*(2), 139-143.

Jacobsen, J. C., Vanderwerker, L. C., Block, S. D., Friedlander, R. J., Maciejewski, P. K., & Prigerson, H. G. (2006). Depression and demoralization as distinct syndromes: Preliminary data from a cohort of advanced cancer patients. *Indian Journal of Palliative Care, 12*(1), 8-13.

Jacobsen, J. V., LC; Block SD, Friedlander, RJ; Maciejewski, PK; Prigerson, HG (2006). Depression and demoralization as distinct syndromes: Preliminary data from a cohort of advanced cancer patients. *Indian Journal of Palliative Care, 12*(1), 8-15.

Jacobsen, P. B., Donovan, K. A., Trask, P. C., Fleishman, S. B., Zabora, J., Baker, F., & Holland, J. C. (2005). Screening for psychologic distress in ambulatory cancer patients. *Cancer, 103*(7), 1494-1502.

Jadoon, N. A., Munir, W., Shahzad, M. A., & Choudhry, Z. S. (2010). Assessment of depression and anxiety in adult cancer outpatients: a cross-sectional study. *BMC Cancer, 10*(1), 594.

Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E., & Forman, D. (2011). Global Cancer Statistics. *CA: A Cancer Journal for Clinicians, 61*(2), 69-90. doi:10.3322/caac.20107

Jo¨nsson, B., Hofmarcher, T., Lindgren, P., & Wilking, N. (2016). The cost and burden of cancer in the European Union 1995-2014. *Europen Journal of Cancer, 66*, 162-170.

Joormann, J. (2010). Cognitive inhibition and emotion regulation in depression. *Current Directions in Psychological Science, 19*(3), 161-166.

Joormann, J., & Gotlib, I. H. (2010). Emotion regulation in depression: Relation to cognitive inhibition. *Cognition and Emotion, 24*(2), .281-298.

Jorgensen, L., Laursen, B. S., Garne, J. P., Sherman, K. A., & Sogaard, M. (2016). Prevalence and predictors of distress in women taking part in surgical continuity of care for breast cancer: A cohort study. *European Journal of Oncology Nursing, 22*, 30-36. doi:10.1016/j.ejon.2016.01.004

Julião, M., Nunes, B., & Barbosa, A. (2016). Prevalence and factors associated with demoralization syndrome in patients with advanced disease: results from a cross-sectional Portuguese study. *Palliative and Supportive Care, 14*(5), 468-473. doi:https://doi.org/10.1017/S1478951515001364

Katz, R. C., Flasher, L., Cacciapaglia, H., & Nelson, S. (2001). The psychosocial impact of cancer and lupus: a cross validation study that extends the generality of ‘‘benefit finding’’ in patients with chronic disease. *Journal of Behavioural Medicine, 50*, 561-571.

Kaviani, H., Gray, J. A., Checkley, S. A., Raven, P. W., Wilson, G. D., & Kumari, V. (2004). Affective modulation of the startle response in depression: influence of the severity of depression, anhedonia, and anxiety. *Journal of Affective Disordorder, 83*(1), 21-31. doi:10.1016/j.jad.2004.04.007

Kissane, D. W. (2000). Psychospiritual and existential distress. The challenge for palliative care. *Australian Family Physician, 29*(11), 1022-1025.

Kissane, D. W. (2004). The contribution of demoralization to end-of-life decision making. *Hastings Center Report, 34*(4), 21-31.

Kissane, D. W., Clarke, D. M., & Street, A. F. (2001). Demoralization syndrome: A relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care, 17*(1), 12-21.

Kissane, D. W., & Kelly, B. J. (2000). Demoralisation, depression and desire for death: Problems with the Dutch guidelines for euthanasia of the mentally ill. *Australian and New Zealand Journal of Psychiatry, 34*(2), 325-333.

Kissane, D. W., Wein, S., Love, A., & Lee, X. Q. (2004). The Demoralization Scale: A report of its development and preliminary validation. *Journal of Palliative Care, 20*(4), 269-276.

Klonsky, E. D., Kotov, R., Bakst, S., & Rabinowitz, J. (2012). Hopelessness as a predictor of attempted suicide among first admission patients with psychosis: A 10-year cohort study. *Suicide and Life-Threatening Behavior, 42*(1), 1–10. doi:10.1111/j.1943-278X.2011.00066.x

Korte, J., Bohlmeijer, E. T., & Smit, F. (2009). Prevention of depression and anxiety in later life: Design of a randomized controlled trial for the clinical and economic evaluation of a life-review intervention. *BMC Public Health,, 9*(1), 250. doi:10.1186/1471-2458-9-250

Krebber, A. M. H., Buffart, L. M., & Riepma, I. C. (2014). Prevalence of depression in canc er patients: a meta-analy sisof diagnostic interviews and self-report instruments. *Psycho-Oncology, 23*, 121–130.

Kroenke, C. H., Michael, Y. L., Poole, E. M., Kwan, M. L., Nechuta, S., Leas, E., . . . Chen, W. Y. (2017). Postdiagnosis social networks and breast cancer mortality in the After Breast Cancer Pooling Project. *Cancer, 123*(7), 1228-1237. doi:10.1002/cncr.30440

Kubler-Ross, E. (1969). *On death and dying*. New York: MacMillan.

Lee, C. Y., Fang, C. K., Yang, Y. C., Liu, C. L., Leu, Y. S., Wang, T. E., . . . Chen, H. W. (2012). Demoralization syndrome among cancer outpatients in Taiwan. *Support Care Cancer, 20*(10), 2259-2267. doi:10.1007/s00520-011-1332-4

Lepore, S. J., & Helgeson, V. S. (1998). Social constraints, intrusive thoughts, and mental health after prostate cancer. *Journal of Social and Clinical Psychology, 7*, 89-106.

Leuchter, A. F., Husain, M. M., Cook, I. A., Trivedi, M. H., Wisniewski, S. R., Gilmer, W. S., . . . Rush, A. J. (2009). Painful physical symptoms and treatment outcome in major depressive disorder: a STAR*D (Sequenced Treatment Alternatives to Relieve Depression) report. *Psychological Medicine, 40*(02), 239. doi:10.1017/s0033291709006035

Lloyd-Williams, M. (2000). Difficulties in diagnosing and treating depression in the terminally ill cancer patient. *Postgraduate Medical Journal, 76*(899), 555-558.

Maes, M., Meltzer, H. Y., Stevens, W., Calabrese, J., & Cosyns, P. (1994). Natural killer cell activity in major depression: relation to circulating natural killer cells, cellular indices of the immune response, and depres- sive phenomenology. *Progress in Neuro-Psychopharmacology and Biological Psychiatry, 18*(717-730).

Markus, H. R., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review, 98*(2), 224-253.

Massie, M. J. (2004). Prevalence of Depression in Patients With Cancer. *Jounal of National Cancer Institute Monographs, 32*, 57-71. doi:https://doi.org/10.1093/jncimonographs/lgh014

McCormick, T. R., & Conley, B. J. (1995). Patients' perspectives on dying and on the care of dying patients. *Western Journal of Medicine, 163*(3), 236-243.

Mehnert, A., & Vehling, S. (2011). Cancer patients: Loss of meaning, demoralization and embitterment *Embitterment* (pp. 142-153).

Mehnert, A., Vehling, S., Hocker, A., Lehmann, C., & Koch, U. (2011). Demoralization and depression in patients with advanced cancer: validation of the German version of the demoralization scale. *Journal of Pain and Symptom Management, 42*(5), 768-776. doi:10.1016/j.jpainsymman.2011.02.013

Meissner, W. (2006). Psychoanalysis and The Mind-Body Relation: Psychosomatic Perspectives. *Bulletin of the Menninger Clinic, 70*(4), 295-315.

Meyer, H. M., Sinnott, C., & Seed, P. T. (2003). Depressive symptoms in advanced cancer. Part 2. Depression over time: The role of the palliative care professional. *Palliative Medicine, 17*(7), 604-607

.

Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., . . . Jemal, A. (2016). Cancer treatment and survivorship statistics, 2016. *CA: A Cancer Journal for Clinicians, 66*(4), 271-289. doi:10.3322/caac.21349

Mitchell, A. J., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C., & Meader, N. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncology, 12*(2), 160-174. doi:10.1016/S1470-2045(11)70002-X

Mitchell, A. J., Meader, N., & Symonds, P. (2010). Diagnostic validity of the Hospital Anxiety and Depression Scale (HADS) in cancer and palliative settings: a meta-analysis. *J Affect Disord, 126*(3), 335-348. doi:10.1016/j.jad.2010.01.067

Monti, D. A., Mago, R., & Kunkel, E. J. S. (2005). Depression, cognition and anxiety among postmenopausal women with breast cancer. *Psychiatric Service, 56*(11), 1353–1355.

Moore, S. A., Zoellner, L. A., & Mollenholt, N. (2008). Are expressive suppression and cognitive reappraisal associated with stress-related symptoms? *Behaviour Research and Therapy, 46*(9), 993-1000.

Mullane, M., Dooley, B., Tiernan, E., & Bates, U. (2009). Validation of the Demoralization Scale in an Irish advanced cancer sample. *Palliative Supportive Care, 7*, 323-330.

Murray, N., Sujan, H., Hirt, E. R., & Sujan, M. (1990). The influence of mood on categorization: A cognitive flexibility interpretation. *Journal of Personality and Social Psychology, 59*, 411–425.

Mystakidou, K., Tsilika, E., Parpa, E., Katsouda, E., Galanos, A., & Vlahos, L. (2005). Assessment of anxiety and depression in advanced cancer patients and their relationship with quality of life. *Quality of Life Research, 14*(8), 1825-1833.

Nanni, M. G., Travado, L., Palma, A., Silvestrini, C., & Grassi, L. (2011). Major depression and demoralization in cancer patients: a comparative study between two countries of South Europe, Portugal and Italy. *Psychooncology, 20*, 172-173.

Ng, C. G. (2016). The challenge in making the diagnosis of depression in palliative patients. *Malaysian Journal of Psychiatry, 25*(2).

Ng, C. G., & Hazli, Z. (2016). Development and Validation of the Positive Emotion Rating Scale (PERS). *International Journal of Academic Research, 8*(1), 31-35. doi:10.7813/2075-4124.2016/8-1/A.6

Ng, C. G., Mohamed, S., Kaur, K., Sulaiman, A. H., Zainal, N. Z., Taib, N. A., & group., M. S. (2017). Perceived distress and its association with depression and anxiety in breast cancer patients. *PLoS ONE, 12*(3), p.e0172975.

Ng, C. G., & Zainal, N. Z. (2014). Prevalence of Depression in Cancer Patients: A Review on the Comparison Between Different Regions. *Malaysian Journal of Psychiatry, 23*(2).

Nikbakhsh, N., Moudi, S., Abbasian, S., & Khafri, S. (2014). Prevalence of depression and anxiety among cancer patients. *Caspian Journal of Internal Medicine, 5*(3), 167-170.

Nordin, K., Berglund, G., Glimelius, B., & Sjödén, P. O. (2001). Predicting anxiety and depression among cancer patients: a clinical model. *European Journal of Cancer, 37*(3), 376-384. doi:10.1016/s0959-8049(00)00398-1

Osowiecki, D. M., & Compas, B. E. (1999). A prospective study of coping, perceived control, and psychological adaptation to breast cancer. *Cognitive Therapy and Research, 23*(2), 169-180.

Parker, M. (2004). Medicalizing meaning: Demoralization syndrome and the desire to die. *Australian and New Zealand Journal of Psychiatry, 38*(10), 765-773.

Pasquini, M., & Biondi, M. (2007). Depression in cancer patients: a critical review. *Clinical Practice and Epidemiology in Mental Health, 3*(1), 2. doi:https://doi.org/10.1186/1745-0179-3-2

Pastore, A. L., Mir, A., Maruccia, S., Palleschi, G., Carbone, A., Lopez, C., . . . Palou, J. (2017). Psychological distress in patients undergoing surgery for urological cancer: A single centre cross-sectional study. *Urologic Oncology*. doi:10.1016/j.urolonc.2017.08.006

Penang Cancer Registry. (2010). *Penang Cancer registry Report 2004-2008*. Retrieved from Penang: http://www.moh.gov.my/JKNPenang/default.htm

Pinquart, M., & Duberstein, P. R. (2010). Depression and cancer mortality: a meta-analysis. *Psychological Medicine, 40*(11), 1797-1810. doi:10.1017/S0033291709992285

Polanski, J., Jankowska-Polanska, B., Rosinczuk, J., Chabowski, M., & Szymanska-Chabowska, A. (2016). Quality of life of patients with lung cancer. *Onco Targets Ther, 9*, 1023-1028. doi:10.2147/OTT.S100685

Popat, K., McQueen, K., & Feeley, T. W. (2013). The global burden of cancer *Best Practice & Research Clinical Anaesthesiology, 27*(4), 399-408. doi:https://doi.org/10.1016/j.bpa.2013.10.010

Prasad, S. M., Eggener, S. E., Lipsitz, S. R., Irwin, M. R., Ganz, P. A., & Hu, J. C. (2014). Effect of depression on diagnosis, treatment, and mortality of men with clinically localized prostate cancer. *Journal of Clinical Oncology, 32*(23), 2471-2478. doi:10.1200/JCO.2013.51.1048

Radloff, L. S. (1977). The CES-D scale: A self- report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 1385-1401.

Raes, F., Daems, K., Feldman, G. C., Johnson, S. L., & Van Gucht, D. (2009). A psychometric evaluation of the Dutch version of the Responses to Positive Affect questionnaire. *Psychologica Belgica, 49*, 293-310. doi:http://doi.org/10.5334/pb-49-4-293

Raes, F., Smets, J., Wessel, I., Van Den Eede, F., Nelis, S., Franck, E., . . . Hanssens, M. (2014). Turning the pink cloud grey: Dampening of positive affect predicts postpartum depressive symptoms. *Journal of Psychosomatic Research, 77*(1), 64-69.

Raison, C. L., & Mille, A. H. (2003). Depression in cancer: new developments regarding diagnosis and treatment. *Biological Psychiatry, 54*(3), 283-294. doi:10.1016/s0006-3223(03)00413-x

Reiche, E. M., Nunes, S. O., & Morimoto, H. K. (2004). Stress, depression, the immune system, and cancer. *Lancet Oncol, 5*(10), 617-625. doi:10.1016/S1470-2045(04)01597-9

Richardson, E. M., Schuz, N., Sanderson, K., Scott, J. L., & Schuz, B. (2017). Illness representations, coping, and illness outcomes in people with cancer: a systematic review and meta-analysis. *Psychooncology, 26*(6), 724-737. doi:10.1002/pon.4213

Rickelman, B. L. (2002). Demoralization as a precursor to serious depression. *Journal of the American Psychiatric Nurses Association, 8*, 9-19.

Robinson, S., Kissane, D. W., Brooker, J., & Burney, S. (2015). A systematic review of the demoralization syndrome in individuals with progressive disease and cancer: A decade of research. *Journal of Pain and Symptom Management, 49*(3), 595-610.

Robinson, S., Kissane, D. W., Brooker, J., & Burney, S. (2016). A review of the construct of demoralization: History, definitions, and future directions for palliative care.

American Journal of Hospital Palliative Care, 33(1), 93-101. doi:10.1177/1049909114553461

Robinson, S., Kissane, D. W., Brooker, J., Michael, N., Fischer, J., Franco, M., . . . Burney, S. (2016). Refinement and revalidation of the demoralization scale: The DS‐II—internal validity. *Cancer, 122*(14), 2251-2259.

Roth, A. J., Kornblith, A. B., Batel-Copel, L., Peabody, E., Scher, H. I., & Holland, J. C. (1998). Rapid screening for psychologic distress in men with prostate carcinoma: A pilot study. *Cancer, 82*(10), 1904-1908.

Rudilla, D., Galiana, L., Oliver, A., & Barreto, P. (2016). Demoralization Scale in Spanish-Speaking Palliative Care Patients. *Journal of Pain and Symptom Management, 51*(4), 769-775. doi:http://dx.doi.org/10.1016/j.jpainsymman.2015.11.019

Sansone, R. S., LA;. (2010). Demoralization in patients with medical illness. *Psychiatry (Edgmont), 7*(8), 42.

Santos, V., Paes, F., Pereira, V., Arias-Carrión, O., Silva, A. C., Carta, M. G., . . . Machado, S. (2013). The role of positive emotion and contributions of positive psychology in depression treatment: Systematic review. *Clinical Practice and Epidemiology in Mental Health, 9*, 221–237.

Saracino, R. M., Rosenfeld, B., & Nelson, C. J. (2016). Towards a new conceptualization of depression in older adult cancer patients: a review of the literature. *Aging Ment Health, 20*(12), 1230-1242. doi:10.1080/13607863.2015.1078278

Seligman, M. E., & Csikszentmihalyi, M. (2014). Positive psychology: An introduction *Flow and the foundations of positive psychology* (pp. 279-298). Netherlands: Springer

Seligman, M. E., Steen, T. A., Park, N., & Peterson, C. (2005). Positive psychology progress: Empirical validation of interventions. *American Psychologist, 60*(5), 874-884.

Sellbom, M., Ben-Porath, Y. S., & Bagby, R. M. (2008). Personality and psychopathology: mapping the MMPI-2 Restructured Clinical (RC) Scales onto the five factor model of personality. *Journal of Personality Disorders, 22*(3), 291-312. doi:10.1521/pedi.2008.22.3.291

Sharif, S. P. (2017). Locus of control, quality of life, anxiety, and depression among Malaysian breast cancer patients: The mediating role of uncertainty. *European Journal of Oncology Nursing, 27*, 28-35.

Sin, N. L., & Lyubomirsky, S. (2009). Enhancing well‐being and alleviating depressive symptoms with positive psychology interventions: A practice‐friendly meta‐analysis. *Journal of Clinical Psychology, 65*(5), 467-487.

Sirri, L., & Fava, G. A. (2013). Diagnostic criteria for psychosomatic research and somatic symptom disorders. *International Review of Psychiatry, 25*(1), 19-30. doi:10.3109/09540261.2012.726923

Sisolefsky, F., Rana, M., Herzberg, P. Y., Gellrich, N.-C., & Rana, M. (2017). Screening for psychological distress: A new approach to identify the patient's psychological needs in a pilot study on oral cancer patients. *Journal of Cranio-Maxillofacial Surgery,, 45*(8), 1133-1137.

Slavney, P. R. (1999). Diagnosing demoralization in consultation psychiatry *Psychosomatics, 40*(4), 325-329.

Smith, H. R. (2015). Depression in cancer patients: Pathogenesis, implications and treatment (Review). *Oncology Letters, 9*(4), 1509-1514. doi:10.3892/ol.2015.2944

Snaith, R. P., Hamilton, M., Morley, S., Humayan, A., Hargreaves, D., & Trigwell, P. (1995). A scale for the assessment of hedonic tone the Snaith-Hamilton Pleasure Scale. *The British Journal of Psychiatry, 167*(1), 99-103.

Spiegel, D., & Giese-Davis, J. (2003). Depression and cancer: mechanisms and disease progression. *Biol Psychiatry, 54*(3), 269-282.

Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., . . . Twillman, R. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 68*(5), 875-882.

Strada, E. A. (2009). Grief, Demoralization, and Depression: Diagnostic Challenges and Treatment Modalities. *Primary Psychiatry, 16*(5), 49-55.

Tang, P. L., Wang, H. H., & Chou, F. H. (2015). A Systematic Review and Meta-Analysis of Demoralization and Depression in Patients With Cancer. *Psychosomatics, 56*(6), 634-643. doi:10.1016/j.psym.2015.06.005

Tavakoli, H. R. (2009). A closer evaluation of current methods in psychiatric assessments: A challenge for the biopsychosocial model. *Psychiatry (Edgmont), 6*(2), 25.

Taylor, V., & Ashelford, S. (2008). Understanding depression in palliative and end-of-life care. *Nursing Standard, 23*(12), 48-57.

Thomson, C. A., McCullough, M. L., & Wertheim, B. C. (2014). Nutrition and Physical Activity Cancer Prevention Guidelines, Cancer Risk, and Mortality in the Women's Health Initiative. *Cancer Prevention Research, 7*(1). doi:10.1158/1940-6207.CAPR-13-0258

Ting-Toomey, S. (1999). *Communicating across cultures*. New York: The Guilford Press.

Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-Tieulent, J., & Jemal, A. (2015). Global cancer statistics, 2012. *CA Cancer J Clin, 65*(2), 87-108. doi:10.3322/caac.21262

Torre, L. A., Siegel, R. L., Ward, E. M., & Jemal, A. (2016). Global Cancer Incidence and Mortality Rates and Trends--An Update. *Cancer Epidemiology, Biomarkers and Prevention, 25*(1), 16-27. doi:10.1158/1055-9965.EPI-15-0578

Treadway, M. T., & Zald, D. H. (2011). Reconsidering anhedonia in depression: lessons from translational neuroscience. *Neuroscience and Biobehavioral Reviews, 35*(3), 537-555. doi:10.1016/j.neubiorev.2010.06.006

Trivedi, M. H. (2004). The Link Between Depression and Physical Symptoms. *Primary Care Companion to The Journal of Clinical Psychiatry, 6*(1), 12-16.

Tugade, M. M., & Fredrickson, B. L. (2004). Resilient individuals use positive emotions to bounce back from negative emotional experiences. *Journal of Personality and Social Psychology, 86*, 320–333. doi: 10.1037/0022-3514.86.2.320

Tugade, M. M., Fredrickson, B. L., & Feldman Barrett, L. (2004). Psychological resilience and positive emotional granularity: Examining the benefits of positive emotions on coping and health. *Journal of Personality, 72*(6), 1161-1190.

U.S. Cancer Statistics Working Group. (2013). *U.S. cancer statistics: 1999–2009 incidence and mortality*. Retrieved from Atlanta GA: http://www.cdc.gov/uscs

Vehling, S., Kissane, D. W., Lo, C., Glaesmer, H., Hartung, T. J., Rodin, G., & Mehnert, A. (2017). The association of demoralization with mental disorders and suicidal ideation in patients with cancer. *Cancer, 123*(17), 3394–3401. doi:10.1002/cncr.30749

Vehling, S., Lehmann, C., Oechsle, K., Bokemeyer, C., Krull, A., Koch, U., & Mehnert, A. (2011). Global meaning and meaning-related life attitudes: exploring their role in predicting depression, anxiety, and demoralization in cancer patients. *Support Care Cancer, 19*(4), 513-520. doi:10.1007/s00520-010-0845-6

Vehling, S., Lehmann, C., Oechsle, K., Bokemeyer, C., Krüll, A., Koch, U., & Mehnert, A. (2012). Is advanced cancer associated with demoralization and lower global meaning? The role of tumor stage and physical problems in explaining existential distress in cancer patients. *Psycho‐Oncology, 21*(1), 54-63.

Vehling, S., Oechsle, K., Koch, U., & Mehnert, A. (2013). Receiving palliative treatment moderates the effect of age and gender on demoralization in patients with cancer. *PLoS One, 8*(3), e59417. doi:10.1371/journal.pone.0059417

Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. *Journal of the National Cancer Institute, 101*(21), 1464–1488. doi: http://doi.org/10.1093/jnci/djp336

Vos, T. (2015). Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet, 386*(9995), 743-800. doi:http://dx.doi.org/10.1016/S0140-6736(15)60692-4

Wagner, G. J., & Ryan, G. W. (2004). Relationship between routinization of daily behaviors and medication adherence in HIV-positive drug users. *AIDS Patient Care and STDs, 18*(7), 385-393.

Wakefield, C. E., Fardell, J. E., Doolan, E. L., Aaronson, N. K., Jacobsen, P. B., Cohn, R. J., & King, M. (2017). Participation in psychosocial oncology and quality-of-life research: a systematic review. *The Lancet Oncology, 18*(3), e153-e165. doi:10.1016/s1470-2045(17)30100-6

Watson, D. (2005). Rethinking the mood and anxiety disorders: a quantitative hierarchical model for DSM-V. *Journal of Abnormal Psychology, 114*(4), 522-536. doi:10.1037/0021-843X.114.4.522

Werner-Seidler, A., Banks, R., Dunn, B. D., & Moulds, M. L. (2013). An investigation of the relationship between positive affect regulation and depression. *Behaviour Research and Therapy, 51*(1), 46-56.

White, M. C., Holman, D. M., Boehm, J. E., Peipins, L. A., Grossman, M., & Henley, S. J. (2014). Age and Cancer Risk: A Potentially Modifiable Relationship. *American Journal of Preventive Medicine, 46*((3 0 1)), S7-15.

Wilson, K. G., Chochinov, H. M., Skirko, M. G., Allard, P., Chary, S., Gagnon, P. R., . . . Clinch, J. J. (2007). Depression and anxiety disorders in palliative cancer care. *J Pain Symptom Manage, 33*(2), 118-129. doi:10.1016/j.jpainsymman.2006.07.016

Wingo, P. A., Cardinez, C. J., Landis, S. H., Greenlee, R. T., Ries, L. A. G., Anderson, R. N., & Thun, M. J. (2003). Long-term trends in cancer mortality in the United States, 1930-1998. *Cancer, 97*(Supplement 12), 3133-3275.

Wood, A. M., & Tarrier, N. (2010). Positive clinical psychology: A new vision and strategy for integrated research and practice. *Clinical Psychology Review, 30*(7), 819-829.

World Health Organisation. (2007). *Cancer control : knowledge into action : WHO guide for effective programmes ; Module 2*. Geneva, Switzerland.

World Health Organization. (2008). *The Global Burden of Disease: 2004 Update*. Retrieved from Geneva:

World Health Organization. (2011). *Number of deaths (World) by cause*. Retrieved from http://apps.who.int/gho/data/node.main.CODWORLD?lang=en.

World Health Organization. (2015). *Fact sheet on cancer*. Retrieved from http://www.who.int/mediacentre/factsheets/fs297/en/

World Health Organization. (2018). Process of translation and adaptation of instruments. *Management of substance abuse: Research tools.* Retrieved from http://www.who.int/substance_abuse/research_tools/translation/en/

Yip, C. H., Bhoo Pathy, N., & Teo, S. H. (2014). A review of breast cancer research in Malaysia. *Medical Journal of Malaysia, 69*, 8-22.

Yip, C. H., Taib, N. A., & Mohamed, I. (2006). Epidemiology of breast cancer in Malaysia. *Asian Pacific Journal of Cancer Prevention, 7*(3), 369-374.

Yong, H., Zubaidah, J., Saidi, M., & Zailina, H. (2012). Validation of Malaysian translated distress thermometer with problem checklist among the breast cancer survivors in Malaysia. *Asian Journal of Psychiatry, 5*(1), 38-42.

Zailina, H., Yong, H. W., Zalilah, M. S., & Yong, H. Y. (2011). Psychological distress among breast cancer survivors [Press release]

Zainal, N. Z., Koh, O. H., & Bustam, A. (2012). Depression and anxiety in breast cancer patients undergoing chemotherapy. *Asia-Pacific Journal of Clinical Oncology, 8*, 258-259.

Zainal, N. Z., Nik-Jaafar, N. R., Baharudin, A., Sabki, Z. A., & Ng, C. G. (2013). Prevalence of depression in breast cancer survivors: a systematic review of observational studies. *Asian Pacific Journal of Cancer Prevention, 14*(4), 2649-2656.

Zhang, X., Xiao, H., & Chen, Y. (2017). Effects of life review on mental health and well-being among cancer patients: A systematic review. *International Journal of Nursing Studies, 74*, 138-148.

Zuraida, A. S., Zainal, N. Z., & Ng, C. G. (2014). Exploratory factorial analysis and reliability of the Malay version of centre for epidemiological studies – depression scale (MCES-D) in a group of Malaysian junior doctors. *International Journal of Academic Research, 6*(2), 333-337. doi:10.7813/2075-4124.2014/6-2/b.50