Prevalence of distress in cancer patients undergoing chemotherapy

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Abstract

Aim: Feeling distressed is often a normal reaction to the diagnosis of cancer and cancer treatment. However, if excessive, distress may lead to more disabling conditions such as depression and anxiety. The aims of the study were to determine the prevalence and level of distress in patients with cancer who were undergoing chemotherapy and to examine the associated factors related to psychological distress in these patients.

Methods: Adult patients with confirmed cancer who were undergoing out-patient chemotherapy at the Clinical Oncology Unit, Universiti Malaya Medical Centre were invited to participate in the study. They were assessed on their sociodemographic profiles, clinical history, distress level as measured using the ‘Distress Thermometer’, and problems checklist on practical, family, emotional and physical symptoms. The Hospital Anxiety Depression Scale (HADS) was used by patients to report anxiety and depression.

Results: One hundred and sixty-eight patients with mean age of 50 years participated in the study. The prevalence of psychological distress determined by the ‘Distress Thermometer’ was 51%. HADS found the prevalence of depression/anxiety to be 32%. There was no significant association between distress and the primary site of cancer, the phase of chemotherapy and the sociodemographic profiles except for age ($r = -0.21$, $P = 0.007$). Distress was significantly associated with practical, family and emotional problems. Some of the physical problems such as appearance, breathing, changes in urination, constipation, eating, fatigue, getting around, memory/concentration, nausea, pain and sleep were also significantly associated with distress.

Conclusion: Cancer patients undergoing chemotherapy experienced high level of distress. This finding should alert oncologists that some patients exhibiting these signs of distress may need referral to the mental health team.

Key words: cancer, chemotherapy, distress.

INTRODUCTION

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature and in this case may interfere with the ability of the patient to cope with his or her disease (i.e. cancer), its physical symptoms and its treatment. The term ‘distress’ was chosen because it is more acceptable and less stigmatizing than ‘psychiatric’, ‘psychosocial’, or ‘emotional’. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis.¹

The World Health Organization currently forecasts that 15 million people annually, worldwide, will receive a diagnosis of cancer in 2020, representing a 50% increase from current numbers.² Many individuals have
described diagnosis of cancer as devastating, producing a more alarming response than that of any other disease process. Therefore, we can expect a rise in the number of cancer patients suffering from cancer affiliated distress.

A lot of work has been done recently in determining psychological distress in cancer patients. The prevalence of long-term psychological distress in cancer patients ranges from 20 to 66%. Anxiety is common at crisis points such as the start of a new treatment or the diagnosis of recurrence or illness progression. Depression has been given much attention in cancer patients as depressive symptoms can be a normal reaction, a psychiatric disorder or a somatic consequence of cancer or its treatment. The rate of depression in cancer patients is higher than in the general population and at least as high as the rate associated with other serious medical illnesses.

Most cancer patients receiving chemotherapy experience psychological distress as a result of negative effects of the chemotherapeutic agents. Nausea and vomiting, tiredness or fatigue, sore mouth, reduced fertility, peripheral neuropathy and skin problems are common side-effects of chemotherapeutic agents.

The National Comprehensive Cancer Network (NCCN) has developed guidelines for Distress Management. The panel members responsible for the above guidelines recommend the use of a simple tool for screening distress level because clinically significant distress is frequently overlooked in many patients. It was found that the use of the single-item Distress Thermometer as a tool to identify cancer patients with psychological distress was comparable to the longer measures for screening distress.

Maintaining quality of life is extremely important. Psychological adjustment and its components need to be defined urgently and understood, to identify effective therapeutic approaches targeting mood and anxiety disorders, and, if possible, to prevent their development. Therefore, research on determining the prevalence and level of distress in patients with cancer who are undergoing chemotherapy is required especially at Universiti Malaya Medical Center where a large number of cancer patients are being treated and followed up everyday. It is also interesting to examine the associated factors related to psychological distress in these patients.

METHODS

The present study was conducted at the Clinical Oncology Unit, Universiti Malaya Medical Center over a three-month period from December 2005 to February 2006. Every consecutive patient that came in for chemotherapy during the study period was invited to participate in the study.

Sample selection

Patients 18 years of age and older with confirmed cancer and who were undergoing outpatient chemotherapy were selected. These patients also had good command of the English language or Bahasa Melayu and were able to give verbal consent to participate in the study.

Measurement

1. Demographic variables were collected from the case notes. These included age, sex, marital status, race and religion.
2. The primary site of cancer and the duration of active illness were obtained from the case notes. The number of cycles of chemotherapy received during the interview indicated whether the patient was in the early, middle or end phase of his/her course of chemotherapy. Because the majority of patients received a total of six cycles for a complete course of chemotherapy, cycles 1 and 2 were considered as in the early phase, cycles 3 and 4 as in the middle phase, and cycles 5 and 6 as in the end phase of a course.
3. The level of distress was measured using a simple tool, the Distress Thermometer, which has been validated in several studies. It has also been used in non-English speaking cancer patients. However, the tool has not been validated in Bahasa Melayu and its reliability in our local population has not been determined. The tool is similar to the 0–10 rating scale used to measure pain and serves as a rough single-item question screen, which will identify distress coming from any source, even if unrelated to cancer. The patient places a mark on the scale answering: ‘How distressed have you been during the past week on a scale of 0–10?’ Scores of 4 or more indicate a significant level of distress.
4. The Problem List asked patients to identify their problems in the past week: physical, practical (i.e. transportation, financial), emotional, familial or spiritual.
5. Subjects were given the 14-item self-reporting instrument: the Hospital Anxiety and Depression Scale (HADS). The instrument was designed for medically ill patients and does not include physical symptoms. The HADS contains seven items that assess anxiety and seven items that assess depression. It has been validated in patients with cancer. Scores on the
HADS do not diagnose anxiety and mood disorder; they measure the severity of symptoms that suggest the likelihood that a patient may have a disorder. A total score of 15 or greater or a score of 8 or greater on a subscale suggests that a patient may have anxiety or depressive disorder.

All the questionnaires were available in English and in Bahasa Melayu. They were collected by the investigators.

**Results**

Of the 207 patients who were approached in the chemotherapy daycare center, 168 (81%) patients consented to participate in the study. The non-responders had similar distribution in terms of gender, marital status, primary site of cancer and the duration of active illness compared to the responders. However, the non-responders were much older (mean 60 years of age vs 50 years of age) and there were more patients of Chinese ethnicity.

The socio demographic distribution and the clinical history of the responders are shown in Table 1. One hundred and forty-six patients (86.9%) had either early stage or locally advanced disease treated with curative intent. The remaining patients had metastatic cancer and were receiving palliative chemotherapy.

Using the Distress Thermometer, the measured mean score for distress level was 3.6. Fifty-one percent of all the cancer patients who were undergoing chemotherapy indicated distress levels of 4 or more.

Using the HADS-depression subscale, 14 of 168 patients scored ≥8. Of the 168 patients, 19 scored ≥8 on the HADS-anxiety subscale. For both depression and anxiety subscales, 21 of 168 patients scored ≥8. Therefore, the prevalence of patients that may have had depression was 21% and those that may have had anxiety was 24%. The total prevalence of patients that may have had psychological distress (i.e. depression and/or anxiety) as determined by HADS was 32%.

Further analysis of the correlation coefficient found that the distress score was significantly correlated with HADS-depression ($r = 0.5$, $P = 0.000$) and with HADS-anxiety ($r = 0.7$, $P = 0.000$).

None of the socio-demographic and clinical features were significantly associated with distress except for age where $r = -0.21$ ($P = 0.007$). The younger the patient, the more distressed they were found to be. There was also no significant difference in the distress score of patients with metastatic and non-metastatic cancers.

The list of problems reported by the patients and their association with distress is shown in Table 2.

**Discussion**

People with cancer have to deal with issues and situations that are very frightening and very challenging, and that are likely to cause distress. The prevalence of distress found in the present study is in keeping with findings in other studies. The high level of distress seen in these patients could be normal responses to the threat of the illness, uncertainty, side-effects of chemotherapy.
agents, loss of control or an underlying psychiatric disorder such as depression and anxiety. Normal responses in patients with cancer range from sadness, worrying, fear, isolation, looking for meaning, feeling stigmatized and being secretive. Following the diagnosis of cancer, patients might undergo stages of shock, denial, anger, and then acceptance or depression.

Receiving chemotherapy is an unpleasant experience due to the toxic effects of the chemotherapy drugs. Cancer patients may have more fear, nervousness and anxiety just prior to starting chemotherapy. Uncertainty as to whether or not they will experience and be able to cope with potential severe nausea, vomiting, hair loss, tiredness and other side-effects are their main concerns. Pre-chemotherapy counseling or education should help patients overcome their fear. They can be given practical advice on how to reduce the risk of infection, cope with nausea and vomiting, and manage tiredness, sore mouth, hair loss and other symptoms.21

In the present study, psychosocial problems were significantly associated with distress. Financial difficulty is the main problem because chemotherapy agents are very expensive. At the University Malaya Medical Center, civil servants are helped by the government to pay for their treatment drugs. Poor non-civil servant patients are referred to the medical social work department to receive financial aid. However, worries persist in these patients if they are unable to work and need money to pay for transportation and domestic expenses.

Some of the patients in this study had problems dealing with their partner or children. Trying to juggle roles such as husband, wife, mother, father, daughter, son or breadwinner while trying to cope with cancer and all the emotions that it can cause can seem impossible to patients. Cancer patients should try to be realistic about what they can manage and seek help from their partner, family or friends before things become too much to cope with.

Many studies have been conducted to determine if emotional states affect outcome and prognosis in cancer patients. Faller et al.22 found that emotional state affected the outcome in cancer patients. Depression was found to have either a positive, negative or mixed association with mortality in cancer patients.23,24 Undetected or untreated depression may lead to poor pain control, poor compliance, poor quality of life and less desire for life-sustaining therapy.

During active anticancer treatment, the diagnosis of depression is often missed.25 Therefore, it is important to screen for distress and be able to detect any psychological morbidity, especially depression and anxiety. Oncologists and other medical personnel such as physicians, nurses and social workers, are encouraged to start using a simple tool such as the Distress Thermometer to screen psychological distress. It is easy to administer and takes up little of the time of busy clinics.1 The use of lengthier measures such as HADS will help detect depression and anxiety.20 Various treatment options are available, such as self-help groups, support groups, psychotherapy and psychopharmacology. Psychotherapy can help patients accept the diagnosis of cancer; sort out treatment options; overcome fear, depression, or denial and enhance the patient’s ability to cope with cancer treatment.26

CONCLUSION

In our study, the prevalence of distress was high in cancer patients receiving chemotherapy. Distress was found to be associated with practical, familial and emotional problems, as well as with some physical symptoms that were either common side-effects of chemotherapy or associated with disease progression.

Regular counseling sessions may help alleviate some family and emotional problems experienced by these patients. Oncologists and chemotherapy nurses need to
be more attentive to signs and symptoms related to the side-effects of treatment or disease process, and offer as much supportive therapy as appropriate. Formal psycho-oncology services should be established to enable those involved in the care of cancer patients to work more closely with mental health teams to optimize the management of these patients.

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REFERENCES