SCREENING FOR PSYCHOSOCIAL DISTRESS IN PATIENTS WITH HEMATOLOGICAL MALIGNANCIES AND IDENTIFYING SPECIFIC FACTORS ASSOCIATED WITH DISTRESS THROUGHOUT PHASE OF DISEASE

A Chapter Style Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Public Health in Community Health Education

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ABSTRACT


The diagnosis of a hematological malignancy and its treatment can lead to symptoms and problems that affect quality of life. An important task of the healthcare system is to assess, monitor, and prevent such symptoms and problems in order to help patients live as fully as possible with their disease. Despite a general acknowledgment of the importance of the patients’ health related quality of life (HRQoL), relatively few studies have investigated this issue in hematological patients. The purpose of this study was to measure the level of distress and identify factors that were associated with distress in patients with a hematological malignancy.

The population of interest for this study includes individuals receiving care at the Gundersen Lutheran Center for Cancer and Blood Disorders for hematological disorders consisting of Hodgkin’s Lymphoma (HL), Non-Hodgkin’s Lymphoma (NHL), Multiple Myeloma (MM), and Chronic Lymphocytic Leukemia (CLL). Patients with hematological malignancies coming to Gundersen Lutheran to receive care from a hematology physician were asked to complete the NCCN Distress Thermometer and Hospital Anxiety and Depression Scale (HADS) stress surveys. If distress was indicated through these measures, medical records were scanned to check for a medical history of anxiety, depression, and other distress symptoms in general. Participants were assessed and compared based on age, sex, marital status, diagnosis, phase of disease, other disease burden, and specific indicators that cause the most distress in their everyday lives. Demographic factors associated with distress to the greatest degree were age and sex. Phase of disease presented varying degrees of distress levels amongst participating patients as well. Furthermore, distress associated with another disease was delineated and identified between the cancer-specific measurement tool of the Distress Thermometer and the broad-based Hospital Anxiety and Depression Scale. Further analysis was also conducted with collaboration of the Charlson co-morbidity index (CCI). Overall, specific factors were identified that were associated with the greatest amount of distress and provided indications for follow-up care by a medical provider.

Keywords: Charlson comorbidity index, chronic lymphocytic leukemia (CLL), distress thermometer (DT), Hodgkin’s lymphoma (HL), Hospital Anxiety and Depression Scale (HADS), multiple myeloma, (MM), National Comprehensive Cancer Network (NCCN), non-Hodgkin’s lymphoma (NHL)
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CHAPTER I

BACKGROUND

Background

Thomas Paine once said, “The real man smiles in trouble, gathers strength from distress and grows brave by reflection” (Chicken Soup for the Cancer Survivor’s Soul, p. 53). In some instances of one’s life, this may be true; however, within the realm of hematological malignancies, distress can become an issue yet to be resolved. According to the National Comprehensive Cancer Network (NCCN), “Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (NCCN Distress Management, p. 6). Furthermore, distress not only ranges from normal, common feelings of worry, fear, and sadness, it can evolve into disabling entities of panic, anxiety, social isolation, depression, and overall emotional and spiritual crisis.

The diagnosis of a hematological malignancy and its treatment can lead to symptoms and problems that affect quality of life. An important task of the healthcare system is to assess, monitor, and prevent such symptoms and problems in order to help patients live as fully as possible with their disease (Johnsen et al., 2009). This has only become more relevant as the survival has increased, and the task is particularly important for diseases that may not be curable. Despite a general acknowledgement of the importance of the patients’ health related quality of life (HRQoL), relatively few studies have investigated this issue in hematological patients (Johnsen et al., 2009).
In 2005, a review by Johnsen and colleagues (2009), found that only eight studies investigated health-related quality of life (HRQoL) and stress in patients with chronic lymphocytic leukemia (CLL). Chronic lymphocytic leukemia (CLL) is the most common adult leukemia in the Western Hemisphere, accounting for more than 20% of all leukemias (Holzner, Kemmler, Kopp, Nguyen-Van-Tam, Sperner-Unterweger, & Greil, 2004). The course of this disease is highly variable and is dependent on the stage of disease at diagnosis and the presence or absence of certain clinical, biological and molecular risk factors. CLL is different from other types of cancer with regard to asymptomatic patients in stages 0-2 of the disease not being treated at all for the disease as therapy does not present a survival advantage in early-stage CLL patients. Therefore, with prevalence of asymptomatic chronic lymphocytic leukemia patients, none of the identified studies investigated patients who had never received treatment, measured distress in a random sample of CLL patients, or had specific factors that cause distress and affect quality of life as their primary objective (Santos, et al., 2006).

Much about the diagnosis, staging and treatment for chronic lymphocytic leukemia is known in today’s medical society there are few studies investigating the level and causes of distress and thus, the overall quality of life of patients with CLL. This statement is especially significant due to the fact that CLL is considered to be the most common form of leukemia (Holzner, 2004). A possible reason for this may be that a vast proportion of patients suffering from CLL go without treatment for several years creating the perception that CLL patients “live a relatively normal life” and often die from other causes. Therefore, level of distress is not perceived as much of an issue as it is in patients with other types of malignant disease. Therefore, psychosocial correlates should and are of particular interest because of the
challenging observational treatment or “watchful waiting” that is crucial to the management of early and indolent chronic lymphocytic leukemia.

Similarly, only a few studies of distress have been conducted for multiple myeloma (MM). Multiple myeloma is a systemic disease and is a disseminated B-cell malignancy of mature and immature plasma cells and is the most prevalent and aggressive plasma cell neoplasm (Poulos, Gertz, Pankratz, & Post-White, 2001). Multiple myeloma comprises 10% of hematological malignancies (Sherman, Simonton, Latif, Spohn, & Tricot, 2004). There are cardinal clinical features to multiple myeloma, including monoclonal protein levels, increased plasma cells in the bone marrow, lytic bone lesions or generalized osteoporosis, hypercalcemia, and anemia (Sherman, Simonton, Latif, Spohn, & Tricot, 2004). Along with these specific cardinal features of MM, pain is the single symptom that significantly impacts the level of distress in those with multiple myeloma.

Pronounced distress can occur from skeletal pain, fatigue, and impaired physical functioning. Furthermore, unrelieved pain is recognized to be a source of psychological symptoms. Direct relationships clearly exist among, pain, mood, distress, and quality of life in patients with multiple myeloma. This was relevant when patients with myeloma were studied and compared by using the Profile of Mood States (POMS), those with pain had higher scores of distress, anxiety, and depression (Poulos, Gertz, Pankratz, & Post-White, 2001).

Little research has focused on distress and quality of life among multiple myeloma patients. Current findings suggest that a substantial proportion of patients experience elevated emotional distress and poor physical functioning, even prior to beginning demanding treatment protocols. More than one-third of MM patients exceed cutoff scores for general emotional distress and a similar proportion has clinically elevated levels of anxiety and a somewhat smaller
report depressive symptoms (Sherman, Simonton, Latif, Spohn, & Tricot, 2004). Therefore, it is clear that distress level adjustment and quality of life are significantly disrupted for many multiple myeloma patients even prior to beginning aggressive treatment and early systematic screening for distress appears to be an important and feasible component of patient care.

Most studies of distress in hematological patients have either focused on long-term survivors or have been part of clinical trials investigating different treatment regimens (Santos, et al., 2006). This is particularly true for one such malignancy, lymphoma. Two lymphomas are included in this study, Hodgkin’s lymphoma and non-Hodgkin’s.

Non-Hodgkin’s Lymphoma (NHL) is one of the fastest increasing cancers and is currently the fifth most common cancer in the United States (Bellizzi, Rowland, Arora, Hamilton, Miller, & Aziz, 2009). The non-Hodgkin’s lymphomas are a diverse group of diseases varying from highly proliferative and rapidly fatal diseases, to some of the most indolent and well-tolerated malignancies found in humans (Hoffbrand, Pettit, & Moss, 2001). Clinical features include presentation of asymmetric, painless enlargement of lymph nodes in one or more peripheral lymph node regions, fever, night sweats, weight loss, anemia, abdominal disease, other organ involvement, and possible oropharyngeal involvement (Hoffbrand, Pettit, & Moss, 2001).

With presentation of clinical symptoms of the disease upon diagnosis and treatment, psychological symptoms are present as well. Patients undergoing treatment often report nausea, vomiting, constipation, and the like, however, other symptoms aside from physical, such as psychological are underreported. Non-Hodgkin’s patients have shown increased levels of listlessness, feeling tense or irritated, worry, anxiety, depression, difficulty remembering and
concentrating, and overall distress much greater than the general population (van den Beuken-van Everdingen et al., 2009).

Furthermore, psychosocial sequelae among non-Hodgkin’s cancer survivors have been the subject of previous investigations, but the generalizability of these findings are often limited by small sample sizes, data derived from single institutions, and lack of a control group. Furthermore, these studies do not provide consistent results. Koocher and O’Malley suggested that many survivors of non-Hodgkin’s lymphoma were at increased risk for maladaptive psychosocial sequelae, and recent research by others has reported at least moderate emotional difficulty, including depression and symptoms of posttraumatic stress. Other investigations have demonstrated behavioral adjustment problems and preoccupation with somatic concerns lowered self-esteem and body image and other psychosocial adjustment problems. This can also be said for Hodgkin’s lymphoma, but differences can be found as well within diagnostic and disease symptom circumstances.

Hodgkin’s is a malignant lymphoma in which Reed-Sternberg (RS) cells are found. It appears that the characteristic RS cells and the associated abnormal mononuclear cells are neoplastic whereas the associated inflammatory cells are reactive (Hoffbrand, Pettit, & Moss, 2001). The Reed-Sternberg cell is of B-lymphoid lineage and is often derived from a B cell with a “crippled” immunoglobulin gene (Hoffbrand, Pettit, & Moss, 2001). Most patients present with painless, non-tender, asymmetrical, firm, and rubbery enlargement of superficial lymph nodes, fever, weight loss, night sweats, weakness, fatigues, and possible spleen enlargement, and mediastinal involvement (Hoffbrand, Pettit, & Moss, 2001).

Currently, a high incidence of the disease is prevalent and thankfully a cure is obtainable. The overall cure rate of Hodgkin’s lymphoma is 70% with patients who achieve long-term
disease free survival, made possible by chemotherapy and/or radiotherapy. Patients undergoing
treatment have displayed levels of anxiety, depression, distress, worry, concentration, and overall
fatigue greater than that of the general population and those with other cancers (van den Beuken-
van Everdingen et al., 2009). Furthermore, there is a strong correlation between fatigue and
psychological distress with both having a significantly negative effect on overall quality of life
(van den Beuken-van Everdingen et al., 2009).

Completion of treatment also puts survivors at risk for the long term toxicities of the
treatment, as well as, lasting effects of the disease. There can be psychosocial, as well as,
physical sequelae years after treatment. With this said, there has been increased advocacy of
Survivor Care Plans due to many cancer survivors becoming lost in the transition from cancer
patient to cancer survivor. Furthermore, many of the non-pain symptoms, such as distress and
other psychological disorders, remain untreated, although effective treatment is available for
most symptoms. Therefore, this illustrates the need for better education about distress symptoms
and symptom control and the need for action in the care plan of patient with Hodgkin’s
lymphoma.

To the investigative team’s knowledge, there exists no study assessing stress and
indentifying specific factors that cause stress for hematological patients throughout the stages of
the disease. Such a study would provide clinically valuable information. Therefore, this study
will investigate and aims to indicate which aspects of one’s life cause significant distress and
point to the challenge of alleviating this impact on health-related quality of life.

**Purpose of the Study**

The purpose of this study is to measure the level of distress and identify factors that are
associated with distress in patients with a hematological malignancy. The phase of the disease
will be diagnosis, treatment, observation or remission. The population of interest for this study includes individuals receiving care at Gundersen Lutheran Center for Cancer and Blood Disorders for a hematological disorder consisting of Hodgkin’s lymphoma (HL), non-Hodgkin’s lymphoma (NHL), multiple myeloma (MM), and chronic lymphocytic leukemia (CLL).

Need for the Study

The need for the study has been based upon previous research by the Gundersen Lutheran Center for Cancer and Blood Disorders medical team. The study was conducted in 2006 and lead by Dr. Craig Cole. Research consisted of identifying significant levels of distress as indicated by the NCCN Distress Thermometer (DT). In the study, a distress level of four or greater was considered significant in a population of patients with a wide array of hematological malignancies. Thus, after I had a personal conversation with Dr. Cole, it was brought to my attention that a need for a more in depth follow-up study was still at the forefront with the medical staff.

The 2006 research indicated that distress is present in patients with a hematological malignancy, however, the factors and overall cause of such significant distress levels was unknown. Therefore, with a follow-up study such as this, specific factors that allude to distress will be identified and distress levels will be assessed to a greater extent than previously done. Furthermore, with four specific groups chosen, CLL, MM, HL, and NHL, the investigator will have more valuable time to depict between factors and dispense valuable information to the medical providers. The hematology providers at the Gundersen Lutheran Center for Cancer and Blood Disorders will attain a greater knowledge base about distress and the factors that cause distress in order to deliver care that not only treats the physical aspects of a patient, but the emotional and mental as well. Overall, the patient will gain greater confidence in the care
received as they become aware that not only is treatment given for their disease, but the factors that affect their quality of life apart from the physical frustrations of cancer.

**Problem Statement**

The diagnosis of a hematological malignancy and its treatment can lead to symptoms of distress and problems that affect quality of life. With prevalent distress levels among hematological patients, it has recently become an important task of the healthcare system to assess, monitor, and prevent such symptoms and problems in order to help patients live as fully as possible with their disease. Therefore, despite a general acknowledgment of the importance of the patients’ distress levels and its effects on health related quality of life (HRQoL), relatively few studies have investigated this issue in hematological patients.

**Research Questions**

1.) To what extent are hematological patients burdened by symptoms and problems of distress?

2.) What factors are associated with the most distress?

3.) What factors that are associated with distress deserve attention for follow-up activity by a medical provider?

**Assumptions**

In order to successfully carry out the study, assumptions for the study include honest responses by the patient upon correct completion of the two questionnaires and willingness of patients to participate in the study. It is assumed if distress is present in a patient, honesty and consent will be obtained in order to receive care for distress and other psychological symptoms affecting quality of life.
Delimitations

Delimitations for this study include proper diagnostic identification of a candidate for the study and correctly administering the survey materials for completion. Proper diagnostic identification includes a candidate receiving care for one of the four hematological malignancies. Secondly, we may de-limit the amount of distress factor data collected as we are focusing on only four groups of hematological disorders, Hodgkin’s lymphoma (HL), non-Hodgkin’s lymphoma (NHL), chronic lymphocytic leukemia (CLL), and multiple myeloma (MM). Thirdly, data will only be collected throughout the extent of six months, which expedites attainment of results and further completion of the study, however, limits the amount of data collected.

Limitations

Research has demonstrated differences in ethnic groups regarding cancer, therefore, an important limitation of this study is that few minority participants will be included in the sample, despite what is known about ethnic disparities. From these known differences in the cancer realm, the results of the present study may not be generalizable to a more ethnically diverse group of patients with multiple myeloma, chronic lymphocytic leukemia, Hodgkin’s lymphoma, or non-Hodgkin’s lymphoma. Therefore, if a small number of ethnically diverse patients are identified, a limitation does not occur, however, if a large number is present, a limitation is as well.

In addition to this possible limitation, this study only involves patients with a diagnosis of multiple myeloma, chronic lymphocytic leukemia, Hodgkin’s lymphoma, or non-Hodgkin’s lymphoma. With this said, other researchers or cancer care institutions will be able to compare the results of this study based upon patients seen with a hematological malignancy. However,
comparison of these results to levels of distress in patients with any type of malignancy may not correlate, which indicates another possible limitation to this study.

Finally, it is unknown as to how many patients will be seen daily, weekly, or monthly for a hematological malignancy at the Gundersen Lutheran Center for Cancer and Blood Disorders, especially within the four categories chosen for the study as this can be affected by the cancellation or rescheduling of an appointment. Therefore, this presents the possibility of a limitation as the total number of patients seen and consent to study participation is unknown.

**Definition of Terms**

**Charlson Comorbidity Index:** The Charlson co-morbidity index predicts the ten-year mortality for a patient who may have a range of co-morbid conditions such as heart disease, AIDS, or cancer (a total of 22 conditions). Each condition is assigned with a score of 1, 2, 3 or 6 depending on the risk of dying associated with this condition. Then the scores are summed up and given a total score which predicts mortality (Valderas, Starfield, Sibbald, Salisbury, & Reland, 2009).

**Chronic Lymphocytic Leukemia (CLL):** One of the four main types of leukemia caused by the change to the DNA of a single cell called a lymphocyte. (Essential Haemotology, p. 191).

**Distress Thermometer:** Screening tool for measuring distress created by the NCCN. (NCCN Distress Management, p. 12).

**Etiologic:** An approach to determine whether distress is the result of somatic symptoms, the cancer itself and its treatment, or a result of anxiety and depression. (Weinberger, Roth, & Nelson, 2009).

**Exclusive:** An approach that excludes somatic symptoms in order to determine the cause of distress. (Weinberger, Roth, & Nelson, 2009).
Hodgkin’s Lymphoma (HL): A type of cancer originating from white blood cell, lymphocyte, and is characterized by the orderly spread of disease from one lymph node group to another. (Essential Haemotology, p. 199).

Inclusive: An approach that includes only somatic and depressive symptoms in an attempt to determine cause of distress. (Weinberger, Roth, & Nelson, 2009).


Multiple Myeloma (MM): A type of cancer of the plasma cells in bone marrow. (Essential Haemotology, p. 215).

NCCN: National Comprehensive Cancer Network. An alliance of 21 of the world’s leading cancer centers and is an authoritative source of comprehensive guidelines and resources. (NCCN Distress Management, p. 1).

Neuropathic Pain: Neuropathic pain is caused by damage or disease affecting the central or peripheral portions of the nervous system involved in bodily feelings. Peripheral neuropathic pain is often described as “burning,” “tingling,” “electrical,” “stabbing,” or “pins and needles.” (Weinberger, Roth, & Nelson, 2009).

Nociceptive Pain: Nociceptive pain is caused by stimulation of peripheral nerve fibers that respond only to stimuli approaching or exceeding harmful intensity (nociceptors), and may be classified according to the mode of noxious stimulation (Weinberger, Roth, & Nelson, 2009).

Non-Hodgkin’s Lymphoma (NHL): cancer that originates in one’s lymphatic system and causes tumors to develop from lymphocytes. (Essential Haemotology, p. 204).

Reed-Sternberg Cell (RS): A giant binucleated or multi-nucleated acidophilic cell in the tissues of Hodgkin’s Disease patients. (Essential Haemotlogy, p. 199).
**Substitutive:** An approach that does not offer a clear advantage to determine the cause of depression with the incorporation of new criteria relating to distress. (Weinberger, Roth & Nelson, 2009).
CHAPTER II

LITERATURE REVIEW

Introduction

Health is a valuable entity to numerous individuals and yet has no guarantees. In 1947, the World Health Organization (WHO) defined health as “a state of total physical, mental, and social well-being and not exclusively the absence of disease”. Recently, the same institution has created another definition stating that, “Health is a biological and social category in dialectical unit with disease, and expresses the level of physical, mental, and social development of the individual and of the collectivity at every historical moment in the development of society”. As one can see with either definition presented by the WHO, mental health plays a crucial role in the overall health of any individual and has become a primary focus in delineating between various aspects when treating and curing an individual burdened by a hematological malignancy.

The implementation of an evaluation process of psychosocial distress in hematological patients is an important issue. According to numerous hematology experts, the transfer of psychological and overall mental and emotional findings into daily practice has been insufficient (Mergenthaler, Heymanns, Koppler, Thomalla, van Roye, Schenk, & Weide, 2010). This has led most hematologists to rely on their own instincts and estimates when assessing their patients’ distress level. This can result in a wide array of miscalculations of the patients’ current distress level poor judgment pertaining to the care administered. With this said, Mergenthaler and colleagues (2010), have found that an important aim of current research is to systematically and
effectively identify patients who are suffering from high emotional distress as a precondition to find appropriate measures to improve their situation.

With this said, it is the hematologists’ duty not only to monitor and care for the patients’ physical conditions due to the malignancy, but also to assess and care for a patients’ psychological health as well. Although studies suggest that physicians’ tend to strongly underestimate their patients’ psychosocial distress when relying on their own personal background and instincts, only between 10% and 14% of cancer specialists are using standardized screening instruments (Mergenthaler, Heymanns, Koppler, Thomalla, van Roye, Schenk, & Weide, 2010). This can be due to both the subjective perception of distress and the way a patient expresses distress issues to the provider, as this can vary to a great extent. Therefore, standards have to be established and implemented in order to create a reliable and efficient way to identify patients that require specific care not only for their current phase of a hematological malignancy, but their high level of distress as well.

**Medical Care Phases**

**Diagnosis**

Being diagnosed with cancer is a highly stressful experience. The diagnosis brings acute emotional distress, and individuals struggle with questions about why the disease struck them, its significance for their future, and the changes that may follow. After receiving a cancer diagnosis, hope has shown to be an important factor in the lives of cancer patients (Yildirim et al., 2009). Hope can improve physical and mental well-being and it is a vital factor when coping with stress and enhancing one’s quality of life during periods of high stress (Yildirim et al., 2009).
In contrast, hopelessness has been associated with diminished physical, psychological, mental, and spiritual health, which is also found during the diagnosis phase (Yildirim et al., 2009). Loss of hope, accompanied by narrowing expectations that the treatment will bring about a cure is believed to reduce patients’ quality of life. Overall, hopelessness is a psychological response to cancer during the diagnosis phase, a diagnostic symptom of depressive disorders, and strongly associated with suicidal tendency (Yildirim et al., 2009). Greer and Watson (1987) described hopelessness as one of the five characteristic reactions of patients to a diagnosis of cancer as the physical illnesses can easily demoralize patients. Demoralization occurs due to the length of the illness, difficulty with treatment, an association with a perceived loss of control, reduced social engagement, and the uncertainty of prognosis (Yildirim et al., 2009).

Thus, the task for the patient recently diagnosed with cancer is to incorporate the diagnosis, and all that comes with it, into existing beliefs of meaning in life in order to cope with the event that befell them. The patient either reworks the diagnosis to make it fit existing beliefs or revises beliefs to better match the experience, a major mental task and start of coping strategies (Jim, et al., 2007). A common coping strategy, acceptance and positive reinterpretation, may lead to a greater sense of meaning in life through the reevaluation of the diagnosis as less negative (Jim, et al., 2007). At least some positive evaluation of a traumatic event is necessary for growth to occur. Furthermore, patients’ who reevaluate the traumatic event of the diagnosis may find it to be an opportunity for personal growth (Jim, et al., 2007).

Social support and active coping, such as, seeking out others or developing a plan of action, may also help patients’ find meaning by developing engagement and emotional expression to others (Jim, et al., 2007). In turn, expression creates further processing of the diagnosis event and its significance, and enables patients’ to view the diagnosis from a more
meaningful perspective (Jim, et al., 2007). Active coping may also impact meaning in life by increasing feelings of self-efficacy and personal control (Jim, et al., 2007). Changing one’s behavior, such as, calling a medical provider to ask a question about their diagnosis and treatment to follow rather than continuing to worry, provides evidence to a patient that he or she is, indeed, trying to improve a difficult situation or solve a problem (Jim, et al., 2007).

Religious coping, such as praying and attending religious services, may help to shape a patients’ meaning in life after cancer diagnosis by providing a framework or system of beliefs that answers many of the issues with which some patient’s struggle (Jim, et al., 2007). For example, in one study, 64% of women recently diagnosed with breast cancer reported that their religious faith helped them to make meaning of the cancer experience (Feher & May, 1999). Patients may come to conceptualize the diagnosis as part of a larger plan or something that has greater meaning for one’s life rather than experiencing cancer as a random event (Jim, et al., 2007).

Aside from the previous mechanisms one may use to accept a cancer diagnosis, three other coping mechanisms are also utilized by cancer patients as a means to maintain a sound mentality and a more positive spin on what is felt to be a dismal time. The three mechanisms are instrumental coping, appraisal-focused coping, and emotion-focused coping (Van der Zee, et al., 2000). Instrumental coping is when a patients’ management of the problem causes distress through elimination or modification of the conditions giving rise to it. Secondly, appraisal-focused coping is when a patient changes the perception of the meaning of the experience in order to neutralize the problem. Finally, emotion-focused coping, involves the regulation of emotional distress produced by the problem (Van der Zee, et al., 2000).
Thereby, instrumental coping and appraisal-focused coping may be regarded as active coping strategies, because they represent active attempts to reduce threat either by eliminating the problem or by changing the meaning (Van der Zee, et al., 2000). Although the disease itself is regarded as uncontrollable, cancer patients may use behavioral strategies to deal with the practical problems they are confronted with as a result of their illness, for example by exercising or keeping up a healthy diet to stay in good shape or journaling to keep a sound mind (Van der Zee, et al., 2000). The appraisal-focused strategies encompass mechanisms such as cognitive reinterpretation or attribution and are also referred to as defensive reappraisal or cognitive coping (Van der Zee, et al., 2000). This strategy requires time and effort as a patient needs to go through various steps in order to release themselves from denial of the cancer diagnosis to acceptance. Finally, emotion-focused coping strategies are referred to as passive strategies because nothing is done to reduce the threat itself, the cancer (Van der Zee, et al., 2000). Examples of passive strategies are responding with anger, seeking distraction, wishful thinking, or helplessness (Van der Zee, et al., 2000).

As early as 1984, Lazarus and Folkman defined coping as, “constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of a person”. This definition has held true with the previous portrayal of coping through the first stage of cancer, the diagnosis, and will continue onto the next, treatments.

**Treatment**

The City of Hope National Cancer Medical Center provides a poignant message at the entrance to its campus: “There is no purpose in curing the body if in the process you destroy the soul.” I found this quote to be ideal as the treatment phase consists of destroying the cancer,
providing steps that are closer to a cure and, at the same time, tests a patient’s mental well being daily. The first day of treatment is unexplainable since there are so many questions that have yet to be answered and experiences that await reactions. What does the treatment consist of? How will I feel afterwards? Will it hurt? Will I be strong enough to handle this? Who is here to help me? The list can go on and on as one thing is for sure, anxiety, fear, worry, and fatigue all play a role in the mind set of a cancer patient. If it is not one aspect, it is another, or all at the same time trying to wreak havoc on a patient’s mental stability.

According to the American Cancer Society, “Fatigue, cognitive dysfunction, and depression are very common in cancer patients” (2001). Fatigue is the most widespread adverse symptom related to cancer and cancer therapy (American Cancer Society, 2001). Fatigue can be physical, such as, muscle weakness or lack of stamina, and mental, involving reduced alertness and lack of motivation, or both. Fatigue can have adverse effects on cognitive function and mood.

Symptoms of cognitive and mood disturbances are expected in cancer patients. Advances in the successful treatment of cancer have been achieved largely by an increased aggressiveness of therapy, which now generally combines surgery, radiation, cytotoxic drugs, and immunotherapy (American Cancer Society, 2001). Unfortunately, cancer treatments are not highly specific and place normal tissues and organs at risk. The central nervous system (CNS) is susceptible to many types of cancer treatments, both directed and non-directed against CNS tumors (American Cancer Society, 2001). Furthermore, many medications needed for the treatment of medical complications also cause adverse CNS effects, including immunosuppressive agents used in bone marrow transplantation, antibiotics, steroids, and drugs used for pain and nausea (American Cancer Society, 2001). Medical complications that can
occur during the course of treatments, such as anemia and infection, can also result in cognitive and mood disturbances (American Cancer Society, 2001). Furthermore, both CNS and non-CNS cancers can produce neurodegenerative diseases, as well as, promote the secretion of hormones or neurotransmitters that affect brain function. The effects that cancer treatments have on the brain create a much more frequent and prominent occurrence of mood disorders, such as anxiety and depression, and consequently, overall mental fatigue.

The impact of mental fatigue on the individual may be conceptualized by the three-tiered system developed by the World Health Organization in 1980 addressing impairment, disability, and handicap. Impairment is mental fatigue as a disruption of the efficient function of the brain and includes determination of etiology and severity. Secondly, disability is the impact of mental fatigue on the patient’s ability to perform his or her usual daily activities. Finally, handicap is the impact of mental fatigue on the patient’s subjective well-being, which includes the patient’s overall comfort level and satisfaction. With regards to this model, the American Cancer Society conducted a study and found that within these descriptions of fatigue, the fact that a relationship between depression and fatigue in cancer is generally acknowledged, however, the notion that the relationship implies causality is not. From this, we can concur that fatigue and depression are related beyond doubt, but, the interpretation of this relation is, however, complicated since the symptoms of fatigue and depression, at times, overlap (de Jong, et al., 2004). Cancer fatigue and depression may co-occur without having a causal relationship, because they can both originate from the same pathology (de Jong, et al., 2004).

Also related to fatigue and the cause of depression in cancer patients is the amount of pain one may be in. According to Juver and Vercosa (2008), it is estimated that more than 50% of cancer patients present pain during the course of their disease. Seventy percent to 90% of
patients with advanced disease complain of this symptom, which can be moderate severity or
unbearable in 30% to 50% of the cases. Cancer pain can be acute or chronic, nociceptive,
neuropathic, or mixed and has several causes (Juver & Vercosa, 2008). These causes are tumor
related, treatment related, development of paraneoplastic syndromes, and non-tumor related
(Juver & Vercosa, 2008). Some painful symptoms can be secondary to a combination of the
factors previously mentioned, and in some situations, it is not possible to identify which ones are
involved, which can also be the case when diagnosing depression in a patient with cancer.

Depressive symptoms in cancer patients do not always constitute classical psychiatric
disorders, but psychological disorders that interfere in the quality of life of the individual, such
as fatigue and pain (Juver & Vercosa, 2008). In depression, psychological and somatic
symptoms remain despite the physical improvement, institution of treatment of the disease, and
promising lab results, which is not compatible with the normal sadness in response to losses.
Studies have demonstrated varying results in the incidence of depressive symptoms, but the
prevalence in cancer patients is around 50% to 60% (Juver & Vercosa, 2008).

Despite the knowledge of several clinically effective treatments, noradrenaline,
dopamine, and serotonin, cancer patients are not treated properly in regards to depression and
fatigue. This is attributed to the difficulty of making a diagnosis of depression in patients with
advanced disease, particularly cancer. This difficulty can be a consequence of the intersection
between symptoms of depression and those present in the late stage of the disease.

A present symptom in the late stage of the disease is fatigue. According to Romito,
“Cancer-related fatigue is a distressing, persistent, subjective sense of tiredness or exhaustion
related to cancer or cancer treatment that is not proportional to recent activity and interferes with
usual functioning”. Patients who experience severe and persistent fatigue have a truly impaired
quality of life, as this condition affects their social activities, leisure time, work and responsibilities (Romito et al., 2008). Fatigue is a multi-dimensional syndrome involving both physical and psychological aspects, which are interrelated and mutually influencing. Persistent fatigue has been recognized to be one of the most common, ongoing symptoms reported by patients with a prevalence ranging from 70% to 100% (Romito, et al., 2008).

Although a strong correlation exists between emotional distress and fatigue, the precise relationship between them is not clearly understood. Both depression and anxiety may be characterized by fatigue, but it is also evident that high levels of fatigue may cause emotional distress when value roles and activities are affected. Therefore, it is hard to disentangle a phenomenon like fatigue, and it may be that research on fatigue actually requires a more complex approach to distinguish its cause and effect of depression in cancer patients throughout the treatment phase.

**Follow-Up**

After treatments, a cancer patient is considered to be cured and enters into an observation or remission stage, also known as the ‘re-entry’ phase. The re-entry phase is when cancer survivors are often expected to return to their usual life patterns leading to overwhelming physical and emotional challenges for which most are unprepared. For example, during this time, cancer survivors must adjust to the greatly diminished interaction with health-care providers, as their weekly appointments shift to only periodic follow-up appointments. Patients not only lose the reassurance of their providers monitoring for signs of recurrence through treatment appointments, but now must assume responsibility for self-monitoring. Existing evidence suggests that survivors struggle with this new responsibility, with nearly half of them in
one study reporting that they were super alert, watchful, anxious, or on guard (Allen, et al., 2008).

The completion of treatment also represents a loss of an action plan against the cancer and many survivors become distressed over the loss of their safety net (Allen, et al., 2008). Also, contact with the support of other cancer patients can be experienced as a loss. Furthermore, fear of recurrence is nearly universal and causes significant distress, especially anxiety, affecting quality of life (Allen, et al., 2008). Amidst the distress, there is also a great amount of resiliency that arises during this transitional stage.

The concept of post-traumatic growth suggests that individuals often experience transformations in self-perceptions, life philosophies, and interpersonal relationships following a traumatic experience (Costanzo, et al., 2009). Cancer survivors have reported closer intimate relationships, positive changes in spirituality, and enhanced sense of personal strength, and an increased appreciation of life (Costanzo, et al., 2009). Many survivors share stories about positive attitudinal changes and increased emotional strength that they felt they could summon as a result of their cancer experience. Moreover, the vast majority of those in remission enact positive behavioral changes to promote their health, such as, increasing physical activity, improving dietary habits, and practicing stress reduction (Allen, et al., 2008).

On the one hand, it is possible that these attitudinal and behavioral changes reflect survivor’s efforts to put a positive spin on their cancer experience. On the other hand, this may reflect problem-focused coping strategies that those in remission can naturally gravitate towards in the post-treatment period. If this is the case, the transition period following treatment may represent a window of opportunity to support a survivor’s coping response and reinforce their efforts to improve their health and mental well-being.
A way in which to support a survivor’s coping response is to either enable or maintain a positive mental attitude (PMA) within the cancer survivor. One component of PMA can be described as optimism, which is a common catalyst to reaching proper cognitive, emotional, and behavioral responses (Rom, et al., 2009). Optimists use more positive coping such as problem-focused coping, seeking social support, and emphasizing positive aspects of a stressful situation (Rom, et al., 2009). Optimism also has an effect on expectancies, and optimists are more likely to use positive interpretation and accept the reality of the situation in a constructive way. To achieve the highest level of optimism at all points on the road of remission, a number of cognitive tactics can be embarked upon, such as relaxation, breathing and imagery, positive affirmations, and hope-filled thinking (Rom, et al., 2009).

Relaxation training is an important psychological tactic to reduce pain and tension in injured areas and relieve psychological distress (Rom, et al., 2009). Relaxation can help reduce anxiety, irritability, and fatigue (Rom, et al., 2009). It can also help modify reactions to pain and increase the ability to deal with stress, two factors that those in remission often face (Rom, et al., 2009). Any way that relaxation can be achieved, such as through massage, meditation, listening to music, watching uplifting movies or television shows, praying, reading, and the list goes on, should be attempted on a regular basis during recovery.

Another tactic is breathing and imagery. Breathing combined with imagery is one specific type of relaxation that is often used as a psychological intervention for those who have gone through a traumatic experience (Rom, et al., 2009). A psychological intervention that includes relaxation strategies significantly reduces emotional distress and aids in speeding up the recovery time (Rom, et al., 2009). Furthermore, breathing exercises can also increase relaxation
by reducing negative arousal which makes a patient better able to summon the creative intelligence needed to facilitate an ideal visual image (Rom, et al., 2009).

A third way to achieve a high level of optimism during remission is positive affirmations. Patients should be encouraged to use uplifting statements during recovery because these can generate positive emotions that improve the quality of the remission phase (Rom, et al., 2009).

Finally, hope-filled thinking is the fourth way in which a survivor can achieve optimism. The positive effects of hope-filled thinking during emotional trauma can be profound. For starters, hope-filled thinking, whether drawn from past experiences or introduced by encouraging human contact or positive environmental stimuli, dramatically increases outcome expectations (Rom, et al., 2009). The effects of the lack of positive influences can range from increased risk perception to a negative neurophysiologic effect, either of which can seriously impede those in remission from achieving a fulfilling, emotionally stable life, both in the home and the community (Rom, et al., 2009). Also, knowing what type of thinking to avoid can also increase outcome expectations, leading to a smoother recovery process and an easier transition from patient to survivor throughout the remission phase.

Also, throughout the remission phase, is a concept known as chemo-brain. Chemo-brain is a term used to describe mental short comings, such as lack of concentration and short-term memory loss. Research conducted by Dr. Dan Silverman reveals that agents used to kill cancer cells may also impair normal brain function. Even years after treatment, patients report problems with memory, concentration, multitasking, and word retrieval (Silverman, 2009).

Patients’ who have undergone chemotherapy often report that their thinking skills have turned to mush as they grope for words. They cannot prioritize tasks, much less complete any (Silverman, 2009). Their deficits may lie in specific areas of mental functioning referred to as
cognitive domains. The area of the brain primarily responsible for executive functioning can be found in the frontal cortex (Silverman, 2009). People who demonstrate good executive functioning usually have strong connections between the frontal areas of the brain and deeper brain circuits (Silverman, 2009). These connections lead to areas of the brain particularly important to memory and movement control (Silverman, 2009). When these connections are impaired, we see deficits in impulse control, multitasking or attention set switching, and information retrieval (Silverman, 2009).

Other areas of concern also found by Silverman are information processing speed, language, attention and memory. Silverman states, “Problems with memory and concentration are the hallmarks of post-chemo brain. To learn something, we must first register it and encode it”. Therefore, according to post-chemotherapy memory deficits, loss was found in all memory aspects; declarative, procedural, encoding, verbal, nonverbal, short-term, and long-term. Apart from these results, Silverman also found a link of chemo-brain to depression.

Depression is a separate issue from cognitive impairment, but often when people are depressed they also struggle with memory, concentration, and attention problems (Silverman, 2009). Clearly, the symptoms of post-chemo brain and depression overlap. Specific brain changes correlate with the severity of depression, just as specific brain changes correlate with the severity of short-term memory impairment (Silverman, 2009). Depression is rooted in biology. So are memory problems. Both are forms of neurologic dysfunction.

For some people, feelings of depression are short-lived. For others, the depressed mood persists. Therefore, as the advances in detection and treatment of hematological malignancies continue to thrive, the medical communities’ assessment and treatment of psychosocial distress
Medical Status Assessments

We need to find an answer to properly diagnosing depression, anxiety, and overall distress in cancer patients. When considering psychiatric symptoms in cancer, depression receives the most attention because of its high prevalence, cost, and enormous impact of the individual and family (Weinberger, Roth & Nelson, 2009). A reason in which depression is often under diagnosed is that the symptoms of cancer and the side effects of treatment often overlap with symptoms of depression. Therefore, depressive symptoms may be difficult to separate from other problems associated with cancer, such as pain, anxiety, or difficulty adjusting to the cancer diagnosis (Weinberger, Roth & Nelson, 2009).

This difficulty in diagnosing depression in cancer patients has led to the development of several diagnostic approaches used for the assessment of depression including, inclusive, etiologic, substitutive, and exclusive (Weinberger, Roth & Nelson, 2009). Overall, these categories differ on the symptoms used for diagnosis of depression and whether or not it incorporates the origin of the depression. For example, the etiologic approach determines whether a somatic symptom is either illness or treatment related or a result of depression, whereas, the exclusive approach excludes the somatic symptoms, such as fatigue, appetite, and weight change, that can be seen in many cancer patients (Weinberger, Roth & Nelson, 2009).

For the medical provider, busy clinics and a lack of specific training in identifying depression and anxiety make it unrealistic to conduct a complete diagnostic interview for alleviating distress in general. Also, to help distinguish between the somatic symptoms of depression and anxiety and the side effects of disease, it may also be helpful to discuss
symptoms pertaining to insomnia, mood variation, and loss of interest or pleasure, which offer specific evidence for a diagnosis of depression and anxiety in cancer patients (Weinberger, Roth & Nelson, 2009).

Furthermore, validated questionnaires may also be useful to help the medical provider screen for depression and anxiety. There are four well validated, self-report measures that are commonly used to assess depression: the Hospital Anxiety and Depression Scale, the Center for Epidemiologic Studies on Depression CESD-20, the Beck Depression Inventory, and the Geriatric Depression Scale (Weinberger, Roth & Nelson, 2009).

The Hospital Anxiety and Depression Scale was developed by Zigmond and Snaith in 1983 to assess both anxiety and depression in a non-psychiatric patient population (Weinberger, Roth & Nelson, 2009). The HADS is meant to differentiate between symptoms of depression with those of anxiety experienced by a patient within the last week (Weinberger, Roth & Nelson, 2009). A key strength of the HADS is the lack of item content reflecting somatic manifestations of anxiety and depression, such as fatigues, that might mimic symptoms of cancer or cancer treatment side effects (Jacobsen, 2011). A second measurement that attains distress behaviors and experiences during the past week is the Center for Epidemiologic Studies on Depression CESD-20. The CESD-20 was developed in the 1970s by Lenore Radloff while she was a researcher at the National Institute of Mental Health (Weinberger, Roth & Nelson, 2009). The CESD-20 is one of the most common screening tests for helping a patient determine only their depressive feelings and behaviors (Weinberger, Roth & Nelson, 2009).

A third distress assessment tool used by healthcare professionals and researchers is the Beck Depression Inventory. The 21-question multiple-choice self-report inventory is one of the most commonly used instruments for measuring the severity of depression (Weinberger, Roth &
Nelson, 2009). The BDI was created by Dr. Aaron Beck in 1961. In 1978, the BDI was revised as the BDI-IA and then the final and most current version, the BDI-II was published in 1996 (Weinberger, Roth & Nelson, 2009). In its current version the questionnaire is designed for individuals aged 13 and over, and is composed of items relating to symptoms of depression such as hopelessness and irritability, cognitions such as guilt or feelings of being punished, as well as physical symptoms such as fatigue and weight loss (Weinberger, Roth & Nelson, 2009).

The final distress measurement tool is the Geriatric Depression Scale. The Geriatric Depression Scale is a 30-item self-report assessment used to identify depression in the elderly (Weinberger, Roth & Nelson, 2009). The scale is commonly used as a routine part of a comprehensive geriatric assessment. One point is assigned to each answer and the cumulative score is rated on a scoring grid. The grid sets a range of 0-9 as "normal", 10-19 as "mildly depressed", and 20-30 as "severely depressed"(Weinberger, Roth & Nelson, 2009).

All in all, these measures are easy and quick to administer and will likely provide a clinician with a baseline measure of depressive symptoms. If a patient develops either a sad mood or loss of interest, administering one of these self-report measures establishes the diagnosis of depression and a baseline from which to measure a symptomatic improvement or decline. However, of the four assessment tools discussed, only one measures anxiety as well as depression. This distress assessment tool is the Hospital Anxiety and Depression Scale.

With regards to this study, the Hospital Anxiety and Depression Scale and the NCCN Distress Thermometer were used in order to depict both anxiety and depression, therefore, allowing the medical providers to assess distress overall for the patient. Pairing the Hospital Anxiety and Depression Scale and the Distress Thermometer is an aspect seen in previous studies regarding all cancers but not a hematological malignancy specifically. Furthermore, the
score attained from the Charlson comorbidity index (CCI) has not been compared to scores from the HADS or DT as other present diseases possibly bring about distress as well.

The Charlson comorbidity index was developed in 1987 based on 1-year mortality data from internal medicine patients admitted to a single New York hospital and was initially validated within a cohort of breast cancer patients (Hall, Ramanathan, Narayan, Jani, & Vijayakumar, 2004). The index encompasses 19 medical conditions weighted 1-6 with total scores ranging from 0-37 (Hall, Ramanathan, Narayan, Jani, & Vijayakumar, 2004). Overall, the CCI has demonstrated excellent predictive validity in numerous cancer-related outcome studies and met criteria for statistical validity by several authors (Hall, Ramanathan, Narayan, Jani, & Vijayakumar, 2004). To the best of our knowledge, the Charlson comorbidity index is the most widely used index within oncology with a simplicity in design that creates adaptations to include additional variables extremely feasible, however, correlations have not been made within a hematological malignancy patient population specifically.

Therefore, not only do the correlations of distress findings between the Distress Thermometer and Hospital Anxiety and Depression Scale measurement tools provide a baseline for future research pertaining to distress in patients with a hematological malignancy, but the delineation of the factors associated with distress as depicted by the Charlson comorbidity index score do as well.

**Physician Insights**

Psychosocial distress is a major burden for patients with a hematological malignancy. Evidence has shown that a high distress level correlates with a number of negative outcomes. Such as, decreased medical adherence, greater desire for death, increased morbidity and length of hospital stays when dealing with their cancer diagnosis and what is to follow (Mergenthaler,
Heymanns, Koppler, Thomalla, van Roye, Schenk, & Weide, 2010). However, the consequences for routine distress care especially within outpatient settings so far have been very little.

Given that the scope of the problem is so substantial and intervention offers the potential to influence many patient outcomes, a first step is to improve identification. Today, most medical providers rely on their own judgments and estimations when assessing a patients’ distress level. As a provider’s personal appraisal has been carried out, studies have shown that physicians tend to strongly underrate their patients’ level of distress (Mergenthaler, Heymanns, Koppler, Thomalla, van Roye, Schenk, & Weide, 2010). Underestimation of distress levels can occur due to both the subjective perception of distress and the variance in which a patient talks about these issues. Furthermore, providers’ time pressures and a reluctance to open up issues that one may not be well equipped or comfortable in dealing with can be other reasons as well (Goldstein, 2011). It has been suggested that cancer specialists have difficulty in identifying emotional complications and tend to have communication behaviors that systematically focus on physical rather than psychological concerns (Goldstein, 2011).

On the other hand, providers who do address distress and utilize standardized screening instruments to identify distress lie within a 10-14% margin (Mergenthaler, Heymanns, Koppler, Thomalla, van Roye, Schenk, & Weide, 2010). With this said, standards have to be established and implemented to reliably identify patients’ requiring specific intervention due to their high level of distress. The establishment of a treatment model that attempts to engage practitioners by providing support, resources and guidance is crucial.

To the best of our knowledge, this is the first study evaluating the Distress Thermometer and Hospital Anxiety and Depression Scale in identifying distress of hematological outpatients. Furthermore, it is also to the best of our knowledge that the Charlson comorbidity index has not
been utilized in delineating the association of a patients’ distress due to a hematological malignancy and presence of other diseases. Therefore, one important aim of this study was to systematically and effectively identify hematological patients’ who are suffering from high amounts of distress as psychosocial aspects of the disease are rarely studied, especially in an outpatient setting. Furthermore, the results of this study will identify the significant need for addressing distress in patients with a hematological malignancy and provide a foundation for future research. Finally, future investigations to follow this study will also help in providing aid regarding distress as appropriate measures to improve a patients’ distress when receiving care throughout the current phase of their cancer can be found and implemented.

Summary

As devastating as the epidemic of cancer has become, there still seems to be hope. Hope that there will be a day in which we are rid of this curable and, at times, incurable disease that not only plagues our nation, but our world. New estimates are given every year as if to prepare everyone for the odds of a diagnosis amongst our society and those that can lead to the possibility of death.

The American Cancer Society estimated in 2009 that approximately 8,510 new cases of Hodgkin’s lymphoma (HL) and 65,980 new cases of Non-Hodgkin’s lymphoma (NHL) would occur annually leaving our society to grasp with the loss of 10,630 treasured individuals. Additionally, 20,580 annual cases of Multiple Myeloma (MM) and 15,490 new cases of Chronic Lymphocytic Leukemia (CLL) will occur, leaving many to deal with meaningful losses as well, 10, 580 and 4,390, respectively. These estimates of new hematological cases are based upon the most recent incidence rates from 41 states and the District of Columbia as reported by the North American Association of Central Cancer Registries (NAACCR), representing about 85% of the
US population. Furthermore, estimated deaths are based on data from 1969-2006 from the US Mortality Data, as well as, the National Center for Health Statistics and the Centers for Disease Control and Prevention from 2009.

Ultimate victory does not come in the final score of a single game: championships sometimes are not won in a single season: it can take years to build a program. Likewise, the outcome of a cancer battle may not immediately be clear, especially when various aspects that accompany the disease, such as distress, are left unresolved due to the lack of education and research. Scott-Sheldon and colleagues (2008), found that the reduction in cancer mortality rests on the patient’s psyche, or a person’s sense of well-being and self-reported happiness. Lowered distress levels of patients often lead to fewer psychological problems after disease (Scott-Sheldon, 2008).

All in all, less disease will no doubt benefit society. Less distress will no doubt benefit those with a hematological malignancy. Therefore, we need to keep those who may hold keys to the future technological, medical, environmental, or social breakthroughs alive and well and implement care that alleviates the distress of those with a hematological malignancy.
CHAPTER III

METHODS

Introduction

Empirical investigations examining psychosocial distress and the need for care of patients with hematological malignancies are rare. Little is known about the use of psychotherapeutic intervention in routine care even though depression, anxiety, and distress are common during the course of cancer. Three large-scale studies suggest that the overall prevalence of distress in unselected cancer patients is greater than 30% (Mitchell, 2007). Distress, anxiety, and depression influence quality of life as well as satisfaction with and participation in medical treatment. At times, a busy cancer care provider can underestimate a patient’s level of anxiety and depression and overlook the care that is needed when symptoms are hidden in its most severe forms (Mitchell, 2007).

To some extent, the low detection rate of distress and related psychiatric disorders appears to be associated with the workload pressure for cancer professionals. Most clinicians in cancer care do not use screening instruments routinely (Mitchell, 2007). In one survey of medical staff, 50% never used a screening tool (Mitchell, 2007). Similarly, in a survey of 123 mixed cancer professionals, 64% relied on clinical skills alone to detect depression and 8% routinely used a screening tool to detect mood disorder or distress (Mitchell, 2007).

For this reason, it has been suggested that short screening instruments might be acceptable and enhance clinicians’ ability to detect mood disorders and distress when present and
exclude distress when absent. Examples of short instruments include the 14-item Hospital Anxiety and Depression Scale (HADS) and Distress Thermometer (DT), both of which are utilized for this study. Therefore, the aim of this study is to determine the level of distress in patients receiving care for a hematological malignancy and factors associated with the greatest amount of distress. Furthermore, we hope to achieve a realistic guideline for clinicians to utilize when providing care to patients.

Sample Population

The sample for the study consists of individuals 18 years of age and older, receiving care for a hematological malignancy at the Gundersen Lutheran Center for Cancer and Blood Disorders. The four diagnoses included in the study are chronic lymphocytic leukemia (CLL), multiple myeloma (MM), Hodgkin’s lymphoma (HL), and non-Hodgkin’s lymphoma (NHL). Further delineation of a diagnosis will be conducted for non-Hodgkin’s lymphoma as different types exist within the realm of this malignancy. Therefore, the type of non-Hodgkin’s lymphoma will be indicated as well. A sample size of at least 150 patients was a chosen goal as the four diagnoses identified for the study are the most common to be diagnosed and treated by Gundersen Lutheran medical providers. The sample size was also chosen based upon patient participation and data collection from the previous hematological distress study conducted in 2006 by the Gundersen Lutheran Center for Cancer and Blood Disorders.

Research Design

The design for this study is descriptive quantitative as it is exploratory in nature. Very little research has been done about distress and its effect on a patient with a hematological malignancy; therefore, much of the study data and results cannot be compared to or based upon previous studies. Thus, this study will provide a foundation for further research.
Instrumentation

The instrumentation consists of two ordinal level questionnaires. The measurement tools include the Distress Thermometer (DT) and Hospital Anxiety and Depression Scale (HADS). The DT is a single-item, self-report measure of psychological distress. The standard research version of the DT consists of an 11-point scale with end-points labeled ‘No Distress’ (0) and ‘Extreme Distress’ (10). Participants are instructed to circle the number that describes their level of distress in the past seven days. Based upon previous psychometric research, a level of four or greater as indicated by the patient yields the best sensitivity and specificity in distinguishing between individuals who are distressed and individuals who are not, as established by cutoff scores on the Hospital Anxiety and Depression Scale (NCCN, 2009).

The DT has shown good sensitivity and specificity in the assessment of depression when compared to the Center for Epidemiological Studies-Depression Scale (NCCN, 2009). Secondly, the Distress Thermometer has been validated by several National Comprehensive Cancer Network studies in patients with different types of cancer and has revealed concurrent validity with the Hospital Anxiety and Depression Scale (NCCN, 2009). Furthermore, the Distress Thermometer has shown concurrent validity when compared to the Hospital Anxiety and Depression Scale.

The Hospital Anxiety and Depression Scale will be used as a supplemental measurement tool to indicate which specific factors have been associated with the most distress and overall general distress in a patient’s life. The HADS has been translated into more than 30 languages and extensively validated in many of these versions (Fritzsche, Struss, Stein, & Spahn, 2003).

The HADS has often been used in studies on cancer patients, especially in patients with leukemia and lymphoma (Montgomery et al., 2003). The HADS consists of fourteen questions.
measuring anxiety and depression in patients with a physical illness (Zigmond & Snaith, 1983). Seven questions relate to anxiety and seven to depression. Each question has a scale of zero to three. A reported score of three identifies that certain feelings, activities, or overall life experiences cause much distress, whereas a score of zero signifies that very little or none of the question relates to the current distress level. Questions and accompanying scores are divided into two categories- anxiety and depression. The reported scores for anxiety and depression align within three categories: normal, borderline abnormal, and abnormal. A total reported score ranging between 0-7 indicates a normal level of distress. Borderline abnormal levels of distress are signified with a score of 8-10, and abnormal levels are portrayed with a score of 11-21.

Internal Validity

Instrumentation

Instrumentation also poses a threat to internal validity if not properly designed. Poorly designed questions can lead to inaccurate answers by the participant (Cottrell & McKenzie, 2005). It is assumed that a patient will answer honestly and accurately, however, if dishonesty or inaccuracy occur internal validity will be affected. Furthermore, if a patient incorrectly completes a questionnaire, the data cannot be included in the study, leaving a result on the amount of data collected and internal validity as well.

Selection Bias

Patients are identified in this study with a diagnosis of CLL, MM, HL, or NHL. Therefore, a selection bias is present in this study as no patients being seen by a Gundersen Lutheran provider for a different hematological malignancy other than the four chosen will be screened for distress. Secondly, a sample of convenience exists within the study as well as the collection of data only includes care received within the Gundersen Lutheran health system. This affects internal validity as the acuity of care received for their cancer from another health system
is not included in the study. Finally, patients for the study are chosen in a non-random manner which may reduce internal validity as well.

**Hawthorne Effect**

A Hawthorne effect is considered to have an impact on internal validity when patients’ attitudes toward being involved in the study affect the way they behave during the study (Cottrell & McKenzie, 2005). This phenomenon could occur during the extent of the study if a patient completes the questionnaires dishonestly in order to remain within the normal range for anxiety, depression, and overall distress when a problem currently exists. A patient may choose to do this in order to maintain focus on the physical aspects of the disease, as opposed to the emotional and psychological aspects. If and when this does occur, the data collected will have an effect on internal validity.

**Process**

The hematological malignancy distress study will include six months of data collection. During these six months, patients diagnosed with chronic lymphocytic leukemia (CLL), multiple myeloma (MM), Hodgkin’s lymphoma (HL), and non-Hodgkin’s lymphoma (NHL) will be screened for current distress level and factors that are associated with distress in their daily life.

A hematological patient with one of the four diagnoses will be identified by the investigator the day before an appointment with a medical provider. After every patient has been identified for an appointment with the practitioners scheduled for the following day, the investigator will create a handout that will include the name and medical record number of the patient, time of arrival, and provider to be seen. The investigator will provide the handout to the medical assistants (MA) at their workstation, along with folders containing questionnaire packets. One folder will be designated for each provider as blue folders indicate physicians and
beige folders indicate physician assistants. The name of the provider will be placed in the upper right hand corner of the folder. All packets will be dispensed in the proper amount in each provider folder.

Upon an identified patient’s arrival, a medical assistant will transfer a patient from the waiting area to a patient room. In the room, the MA will first obtain vital signs and then distribute the questionnaire packet to the patient. The packet will include a welcome letter, consent form, Distress Thermometer (DT) and Hospital Anxiety and Depression Scale (HADS). The welcome letter gives the patient a brief overview of the purpose of the study and need for involvement and the informed consent describes legalities of the study. A patient will then read the consent form and choose to partake in the study. Consent to partake in the study is obtained through the patients’ signature on the consent form. After understanding involvement in the study, the patient will complete the packet by answering both questionnaires in approximately five minutes.

Upon successful completion of the DT and HADS, the packet will be collected by a Medical Assistant (MA), the study investigator, or the medical provider. The gathered information will be reviewed by the investigator and medical provider. If significant distress is displayed by the DT level and HADS scores, a chart review will be conducted by the investigator to determine a previous medical history with certain types of distress, such as anxiety or depression. After a medical history is obtained, the investigator will indicate findings to the medical provider in order for the provider to modify the plan of care for the individual and provide necessary care to alleviate distress.

As appropriate care is given to the patient, the investigator will transfer data into a Microsoft Excel spreadsheet to maintain organization throughout the data collection process.
The spreadsheet will include the medical record number of the patient, name of the patient, diagnosis, stage and current state of disease, gender, age, marital status, Distress Thermometer score, individual Hospital Anxiety and Depression (HADS) question scores, overall HADS depression and anxiety scores, and medical history of overall psychological distress, such as anxiety and depression. The patient’s name and medical record number will be discarded at the conclusion of the data collection period to maintain patient anonymity throughout the data analysis and results phase. Furthermore, the spreadsheet will aid in maintenance of patient participation as patients will complete questionnaires once to prevent bias in results and inaccurate distress level and factor data.

The completed questionnaires will be sorted by the investigator and placed in a file cabinet containing dividers. Each divider will be labeled to identify separate sections for the Distress Thermometer, Hospital Anxiety and Depression Scale, and informed consent sheet completed by the patient. The file will be locked every evening by the investigator in order to maintain patient privacy and confidentiality throughout the extent of the study. Also, as a follow-up, the investigator will make a copy of the informed consent form and mail it to the patient along with a letter expressing gratitude for the individual’s involvement in the study. The letter will include contact information for the patient to utilize if questions arise after participation in the study and give the patient a personal record of involvement in the study.

**Time Frame**

- **July 2010**
  - Meeting with Hematology Staff
  - Meeting with Gundersen Lutheran Medical Foundation
  - Thesis committee selection
• August 2010
  o Select Gundersen Lutheran medical staff involvement
  o Select data collection methods
  o Study Proposal
  o IRB Approval

• September 2010
  o Create Microsoft Excel spreadsheet
  o Data collection
  o Maintain data organization methods

• October 2010
  o Data collection
  o Maintain data organization methods
  o Meeting with Hematology medical staff
  o Finalize Chapter I of thesis
  o Start Chapter III of thesis

• November 2010
  o Data collection
  o Maintain data organization methods
  o Meeting with Hematology Staff and Medical Education
  o Thesis committee meeting
  o Finalize Chapter III of thesis

• December 2010
  o Data collection
- **January 2011**
  - Data collection
  - Maintain data organization methods
  - Meeting with Hematology medical staff

- **February 2011**
  - Data collection
  - Maintain data organization methods
  - Meeting with Hematology medical staff
  - Assign Gundersen Lutheran biostatistician

- **March 2011**
  - Last month of data collection
  - Meeting with Hematology medical staff
  - Meet with Gundersen Lutheran biostatistician
  - Finalize data collection process to proceed to analysis

- **April 2011**
  - Data analysis
  - Meet with Gundersen Lutheran biostatistician
  - Configure results of study
  - Meeting with Hematology medical staff and thesis committee

- **May 2011**
  - Finalize data analysis
Meet with Gundersen Lutheran biostatistician

Configure discussion and conclusion of thesis

Meeting with thesis committee

- **June 2011**
  - Revise and finalize discussion for thesis
  - Revise and finalize conclusion for thesis

- **July 2011**
  - Submit abstract and study materials for publication approval
  - Submit final thesis
  - Present thesis oral defense

**Data Analysis**

Upon the six month completion of data collection, the investigator will begin data analysis to obtain results from the study. Results will indicate distress level and factors associated with each of the four hematological malignancies included in this study-- CLL, MM, HL and NHL. Furthermore, sub-groups analyzed amongst these four types of malignancies will include; age, gender, marital status, hospitalizations, and current state of disease.

In order to delineate between these demographic groups, the investigator will be able to group patients into each demographic by way of the sort and filter functions and create a separate spreadsheet utilized through the Microsoft Excel database. Upon utilizing the sort and filter functions, the investigator will be able to deduce how many patients lie within each specific demographic category. The amount of patients within each category will be attained through the use of the Microsoft Excel AutoSum function.
The amount of patients displaying a significant level of distress will be indicated by the creation of a formula by use of the formula function within the Excel database. A formula needs to be created in order to specifically target the scores reported within the Excel database for the Distress Thermometer and Hospital Anxiety and Depression Scale as this is a separate entity from the sort and filter functions to attain demographics. After the amount of patients with distress has been identified, various correlations pertaining to the demographics of the study can be attained and the three research questions can be addressed.

**External Validity**

External validity is concerned with the ability to generalize study results to other groups and settings beyond those in the current study (Cottrell & McKenzie, 2005). Selection treatment interaction is the first of three threats to external validity in this study. This threat involves the ability of the investigator to generalize results of the study beyond the groups involved. For example, in this study, the target population consists of patients diagnosed with the following hematological malignancies: CLL, MM, HL, or NHL. All four are a type of cancer; however, variance occurs based upon the patient diagnosis. A patient diagnosed with Stage IV Hodgkin’s lymphoma could report greater distress than an individual at Stage II with the same disease. Therefore, results from this study can be generalized to those with a hematological malignancy at a given stage and not for those with a different type of cancer.

Secondly, the location at which the study takes place, the Gundersen Lutheran Center for Cancer and Blood Disorders, allows for results to be generalized to other community-based settings. These settings could include medical centers in general and other cancer treatment centers that diagnose and treat patients with the same hematological malignancies indicated in the study. Therefore, the community-based setting has an impact on external validity.
Finally, there are variations in how time could play a factor on external validity during this study. For starters, data collection occurs over the course of six months, from September through March; higher distress could be exhibited during the winter months due to seasonal depression and holiday stress. Also, the amount of time one has dealt with the disease and the current phase of the disease could have an impact on current level of distress and relate to responses given by the patient.

**Summary**

Distress is a multi-factorial unpleasant emotional experience that can interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress should be recognized, monitored, documented, and treated promptly at all stages of disease. Furthermore, screening should identify the level and nature of distress, while patients, families, and treatment teams should be informed that management of distress is a vital part of total medical care. Therefore, with proper implementation of this study, appropriate information about psychosocial services and provision of appropriate care will be provided at the Gundersen Lutheran Center for Cancer and Blood Disorders and will serve as a foundation for other cancer centers and further research.
CHAPTER IV

RESULTS

Introduction

Cancer is a six-letter word that creates a variety of changes and adjustments in a significant amount of lives throughout this country. The American Cancer Society estimated in 2010 that approximately 8,490 new cases of Hodgkin’s lymphoma (HL) and 65,540 new cases of non-Hodgkin’s lymphoma (NHL) would occur annually leaving our society to grasp with the loss of 1,320 and 20,210 treasured individuals. Additionally, 20,180 annual cases of multiple myeloma (MM) and 14,990 new cases of chronic lymphocytic leukemia (CLL) would occur, leaving many to deal with meaningful losses as well, 10,650 and 4,390, respectively.

These estimates of new cases are based upon the most recent incidence rates from 41 states and the District of Columbia as reported by the North American Association of Central Cancer Registries (NAACCR), representing about 85% of the US population. Furthermore, estimated deaths are based on data from 1969-2006 from the US Mortality Data, as well as, the National Center for Health Statistics and the Centers for Disease Control and Prevention from 2009.

As a national numerical representation is known, it is essential to attain local values as well. In this distress study conducted at the Gundersen Lutheran Center for Cancer and Blood Disorders, a total of 302 hematological patients were identified with 36% (N=110) declining to participate. Therefore, since 110 patients did not consent to participation, the investigator was
able to attain data from 192 patients throughout the six months of data collection. Of these 192 patients, 21 (11%) were diagnosed with Hodgkin’s lymphoma, 82 (43%) with non-Hodgkin’s lymphoma, 42 (22%) with multiple myeloma, and 47 (24%) with chronic lymphocytic leukemia.

With these data clarified, it is important to understand that a diagnosis of cancer is a highly stressful experience. The diagnosis brings acute emotional distress, and individuals struggle with questions about why the disease struck them, its significance for their future, and the changes in their lives and the lives of significant others that may follow. Accepting a cancer diagnosis requires use of various coping skills, surrounding oneself with support from others, such as family and friends, and creating an overall positive environment, an environment to be maintained throughout the course of treatments.

The City of Hope National Cancer Medical Center provides a poignant message at the entrance to its campus: “There is no purpose in curing the body if in the process you destroy the soul.” I found this quote to be ideal as the treatment phase consists of destroying the cancer, providing steps that are closer to a cure and, at the same time, testing a patient’s mental well-being daily.

According to the American Cancer Society (2001), “Fatigue, cognitive dysfunction, and depression are very common in cancer patients” (p. 13). Fatigue is the most widespread adverse symptom related to cancer and cancer therapy (American Cancer Society, 2001). Fatigue can be physical, such as, muscle weakness or lack of stamina, and mental, involving reduced alertness and lack of motivation, or both. Overall, fatigue can have adverse effects on cognitive function and mood.

Also related to fatigue and the cause of depression or anxiety in cancer patients is the amount of pain they may be experiencing. According to Juver and Vercosa (2008), it is
estimated that more than 50% of cancer patients present pain during the course of their disease. Seventy percent to 90% of patients with advanced disease complain of this symptom, which can be moderately severe or unbearable in 30% to 50% of the cases. Moreover, cancer pain can be acute or chronic, nociceptive, neuropathic, or mixed and has several causes (Juver & Vercosa, 2008). These causes are tumor related, treatment related, associated with development of paraneoplastic syndromes, and non-tumor related (Juver & Vercosa, 2008). Some painful symptoms can be secondary to a combination of the factors previously mentioned and, in some situations it is not possible to identify which ones are involved, which can also be the case when diagnosing depression in a patient with cancer (Juver & Vercosa, 2008).

Depressive symptoms in cancer patients do not always constitute classic psychiatric disorders, but psychological symptoms that interfere with the quality of life of the individual, such as fatigue and pain (Juver & Vercosa, 2008). In depression, psychological and somatic symptoms remain despite the physical improvement, institution of treatment of the disease, and promising lab results; these symptoms are not compatible with normal sadness in response to losses. Studies have demonstrated varying results in the incidence of depressive symptoms, but the prevalence of these symptoms in cancer patients is around 50% to 60% (Juver & Vercosa, 2008).

Although a strong correlation exists between emotional distress and fatigue, the precise relationship between them is not clearly understood. Both depression and anxiety may be characterized by fatigue, but it is also evident that high levels of fatigue may cause emotional distress when valued (e.g. wife, husband, employee) roles and activities are affected. Therefore, it is hard to disentangle a phenomenon like fatigue, and it may be that research on fatigue
actually requires a more complex approach to distinguish its cause and effect on depression in cancer patients.

After treatments, a cancer patient is considered to be cured and enters into the remission stage, also known as the ‘re-entry’ phase. The re-entry phase is when cancer survivors are often expected to return to their usual life patterns leading to overwhelming physical and emotional challenges for which most are unprepared. For example, during this time, cancer survivors must adjust to the greatly diminished interaction with healthcare providers, as their weekly appointments shift to only periodic follow-up appointments. Patients not only lose the reassurance of their providers monitoring for signs of recurrence through treatment appointments, but now must assume responsibility for self-monitoring. Existing evidence suggests that survivors struggle with this new responsibility, with nearly half of them in one study reporting that they were especially alert, watchful, anxious or on guard (Allen et al., 2008).

For the oncologist, busy clinics and a lack of specific training in identifying depression and anxiety creates an unrealistic medical care environment able to conduct a complete diagnostic interview for alleviating distress in general even though an increasing awareness of distress in cancer patients is known. A very limited amount of previous literature based upon the types and amount of distress cancer patient’s face is available. Therefore, this study and its findings can provide a foundation for further research and be used as a comparable aid for other studies, an aspect highly unattainable throughout the data analysis process.

Findings

Research Question One: To what extent are hematological patients burdened by symptoms and problems of distress?
Of the 192 participants in the study, a total of 41 (21%) individuals were identified with having a medical history of psychological distress. Taking a step further, of these 41 hematological patients, 7 (17%) were diagnosed with anxiety, 16 (39%) with depression, and 18 (44%) were dealing with both anxiety and depression at the time of the study. However, numerical data collected from both the Distress Thermometer (DT) and Hospital Anxiety and Depression Scale (HADS) measurement tools indicate a greater number than identified through medical record examination.

According to results from the DT, 64 (33%) patients reported a score of 4 or greater, indicating a significant amount of distress as set by the National Comprehensive Cancer Network (NCCN). Along with the identifying distress with scores from the Distress Thermometer, the Hospital Anxiety and Depression Scale had shown a total of 59 (31%) patients who reported scores greater than eight for anxiety, depression, or both. To break this down further, 32 (54%) of the 59 patients displayed a score of greater than eight for anxiety, 5 (8%) for depression and 22 (38%) for both anxiety and depression. Therefore, if one distributes the amount of patients indicating distress between the DT and HADS, a type of concordance occurs as the cancer-specific Distress Thermometer represents 33% and the broad-based Hospital Anxiety and Depression Scale represents a slightly lower 31% of the patients who were seen throughout the course of six months at the Gundersen Lutheran Center for Cancer and Blood Disorders. Therefore, these patients were not only trying to overcome the current phase of their cancer, but psychological distress as well. In Figure 4.1, the percentage of patients who reported a score of 4 or greater on the DT (N=64) and those who reported a score of 8 or greater for anxiety or depression on the HADS (N=59) is represented. Please refer to Figure 1.
Research Question Two: What factors are associated with the most distress?

Sex. In this study, a total of 118 males and 74 females participated. Of the 118 males, 37 (31%) reported a DT score of 4 or greater. Additionally, 17 (14%) males reported a significant level of anxiety including 4 (3%) with depression and 13 (11%) with both anxiety and depression pertaining to the Hospital Anxiety and Depression Scale. Therefore, when you compare the amount of men suffering from distress on the score reported on the Distress Thermometer, 31% of males are represented within this group and the HADS represents 29% (N=34) of the 118 male participants.

On the other hand, a smaller group of women participated in the study with values from this subset indicating a greater percentage of females succumbing to distress as compared with males. Of the 74 females, 29 (39%) indicated distress via the Distress Thermometer with a score of four or greater. Values from the Hospital Anxiety and Depression Scale show that 15 (20%)
reported anxiety, 1 (1%) reported depression, and 9 (12%) reported both anxiety and depression. From these HADS scores, 34% (N=25) of women were suffering from anxiety and depression and the Distress Thermometer indicates that 39% (N=29) were suffering from distress overall. Please refer to Figure 2.

<table>
<thead>
<tr>
<th>Score Category</th>
<th>Female Count</th>
<th>Male Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female HADS Score 8 or Greater</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Male HADS Score 8 or Greater</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Female DT Score 4 or Greater</td>
<td>39</td>
<td></td>
</tr>
<tr>
<td>Male DT Score of 4 or Greater</td>
<td>31</td>
<td></td>
</tr>
</tbody>
</table>

Figure 2. Percentage Comparisons of Distress Displayed from Scores on the DT and HADS by 118 Male and 74 Female Patients Seen at the Gundersen Lutheran Center for Cancer and Blood Disorders 2010-2011.

Findings from the study suggest that gender plays a role in distress as results indicate that females undergo a greater amount of distress than males. When comparing these gender specific data from this study to other literature (i.e. Allen, Juver & Vercosa), the same results occur. Overall, women undergo a greater amount of distress than men for both a hematological malignancy and other malignancies in general.

**Marital Status.** In addition to gender, other demographic data were also collected regarding marital status and is displayed in Table 1. In this study, 145 (76%) participants were married, 33 (17%) were unmarried or had an unknown marital status, 5 (2%) were divorced, and 9 (5%) were widowed. Of the 145 married individuals, 54 (37%) indicated a distress level of 4 or
Hospital Anxiety and Depression Scale scores revealed 29 (20%) with anxiety, 3 (2%) with depression and 12 (8%) suffering with both anxiety and depression. Thus, according to the Distress Thermometer, 37% (N=54) were dealing with distress at the time of the survey and 30% (N=44) indicated issues with anxiety, depression, or both with scores greater than 7 on the HADS.

Additionally, of the 33 unmarried/unknown marital status participants, 8 (24%) indicated a level of 4 or greater for distress on the DT. Further evaluation of this group also displayed 3 (9%) individuals with anxiety, 2 (6%) with depression and 7 (21%) with both anxiety and depression as indicated by reported scores on the Hospital Anxiety and Depression Scale. With this said, 24% (N=8) of unmarried patients displayed distress via the Distress Thermometer and 36% (N=12) relayed depression, anxiety, or both through completion of the Hospital Anxiety and Depression Scale.

Further data also were collected for those participants who were divorced. Of the five divorced patients, one (20%) reported a distress score of 4 or greater on the Distress Thermometer and one (20%) indicated anxiety and depression with completion of the HADS. No divorced individuals were suffering from only anxiety or depression. Therefore, according to both the Distress Thermometer and HADS, 20% (N=1) of this population was dealing with distress and issues related to depression and anxiety.

Finally, data regarding widowed participants were analyzed. Of these 9 patients, 1 (11%) reported distress on the Distress Thermometer and 2 (22%) indicated both anxiety and depression with elevated scores on the HADS. As with the divorced patients, no widowed patients were currently dealing with only anxiety or depression. Thus, according to the Distress
Thermometer, 11% (N=1) were dealing with distress at the time of the survey and 22% (N=2) indicated issues with anxiety and depression with scores greater than 7 on the HADS.

Table 1. Distress Thermometer and Hospital Anxiety and Depression Scale Scores Indicating Adverse Symptoms and the Percentage of Representation of Distress Based Upon the Marital Status Among Study Patients at the Gundersen Lutheran Center for Cancer and Blood Disorders 2010-2011

<table>
<thead>
<tr>
<th></th>
<th>DT Score</th>
<th>HADS Anxiety</th>
<th>HADS Depression</th>
<th>HADS A &amp; D</th>
<th>DT % for All Symptoms</th>
<th>HADS % for All Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=145</td>
<td>54</td>
<td>29</td>
<td>3</td>
<td>12</td>
<td>37%</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N=54</td>
<td>N=44</td>
</tr>
<tr>
<td>Unmarried/Unknown</td>
<td>8</td>
<td>3</td>
<td>2</td>
<td>7</td>
<td>24%</td>
<td>36%</td>
</tr>
<tr>
<td>N=33</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N=8</td>
<td>N=12</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>N=5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N=1</td>
<td>N=1</td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>11%</td>
<td>22%</td>
</tr>
<tr>
<td>N=9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N=1</td>
<td>N=2</td>
</tr>
</tbody>
</table>

**Age.** Another demographic that was analyzed in order to assess the correlation with distress levels was age. The youngest individual who met criteria for the study was 22 and the oldest was 95. However, no patients from the 90-99 age group participated in the study and one of the four patients within the 20-29 age group participated, with no indication of significant distress as addressed by the DT and HADS. Overall, findings from this study suggested that the age range consisting of 50 to 79- year-old individuals was distressed to a greater degree than the
younger or substantially older individuals who participated in the study. To elaborate upon this further, patients within the 60-69 age group revealed the greatest amount of distress on the Distress Thermometer with patients aged 70-79 slightly lower, yet quite distressed. Please refer to Figure 3.

![Figure 3](image_url)

**Figure 3. Age and Distress Among Study Patients at the Gundersen Lutheran Center for Cancer and Blood Disorders 2010-2011**

**Phase of Disease.** Many phases of cancer exist and are also a relevant aspect to data analysis as differing levels of distress occur throughout diagnosis, treatment, observation, and remission. Therefore, the cancer phase in which the participating patient was each experiencing during the study also was analyzed in order to determine its effect on the current level of distress. Of the 192 total patients, 8 (4%) were recently diagnosed, 80 (42%) were undergoing treatment,
34 (18%) had entered the observation phase before full remission and 70 (36%) had finally attained full remission from their malignancy. Results show that all patients recently diagnosed reported distress. Furthermore, the largest number of patients who participated in the study were undergoing treatment at the time of the survey and thus displayed a far greater amount of distress than other patients in another phase of the disease with completion of both the Distress Thermometer and Hospital Anxiety and Depression Scale. Patients who indicated less distress were those in the later non-treatment phase of observation. However, a final indication to be made pertains to remission and the level of distress indicated by those patients. A substantial number (N=24) of remission patients, although cured, remained distressed to some extent at the time of the survey and represent the second largest group in the study. Figure 4.3 displays 17 patients reporting a distress level greater than 4 on the DT and an additional 7 patients reporting anxiety and depression on the HADS. Other patients in remission reported either anxiety (N=10) or depression (N=3) on the HADS. Please refer to Figure 4.

![Figure 4. Phase of Disease and Effect on Distress Level Among Study Patients at the Gundersen Lutheran Center for Cancer and Blood Disorders 2010-2011](image)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Observation</th>
<th>Remission</th>
</tr>
</thead>
<tbody>
<tr>
<td>DT 4 or &gt;</td>
<td>5</td>
<td>30</td>
<td>12</td>
<td>17</td>
</tr>
<tr>
<td>HADS ANX</td>
<td>0</td>
<td>16</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>HADS DEP</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>HADS ANX &amp; DEP</td>
<td>3</td>
<td>9</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>
**Other Disease Burden.** The Charlson co-morbidity index predicts the ten-year mortality for a patient who may have a range of co-morbid conditions (Valderas, Starfield, Sibbald, Salisbury, & Reland, 2009). Twenty-two conditions are assessed, to include diabetes, heart or renal failure, chronic obstructive pulmonary disorder (COPD), AIDS, heart disease and cancer (Valderas, Starfield, Sibbald, Salisbury, & Reland, 2009). Each condition is assigned a score of 1,2,3 or 6 depending on the risk of dying associated with the condition. Then the scores are summed up with the total score predicting mortality. For a physician, it is helpful in knowing how aggressively to treat a condition. For example, a patient may have cancer, but also heart disease and diabetes so severe that the costs and risks of treatment outweigh the short term benefit from treatment of the cancer. Therefore, other health-related conditions could be factors associated with the current level of a patient’s distress in this study.

As presented earlier, 64 of the 192 patients who participated in the study reported a substantial level of distress through the DT with a value of four or greater. DT levels of distress are assumed to be cancer-specific as this is a measurement tool designed and implemented by the National Comprehensive Cancer Network. Therefore, other health ailments that a patient faces are not taken into consideration and could also be factors associated with a patient’s current level of distress. A Charlson comorbidity index (CCI) score was calculated for these 64 patients in order to identify other health ailments and delineate between cancer-related distress and health-related distress overall.

Results showed that 31 (48%) of the 64 patients had a level of 5 or greater on the comorbidity index. Overall, nearly half of the patients had a score ranging from 5 to 7, indicating the presence of another health-related issue aside from cancer. Therefore, cancer not
only played a role in the level of distress of these patients, but other health-related issues became factors associated with their distress, as well.

**Research Question Three:** What factors that are associated with distress deserve attention for follow-up activity by a medical provider?

**Phase of Disease.** The phase of the disease is a factor to emphasize action for follow-up activity by a medical provider in order to alleviate distress. The current cancer phase of diagnosis, treatment, observation, or remission allows a medical provider to carry out a follow-up process with a patient regarding their distress. Patients in the initial diagnosis and treatment phases are seen on a weekly or bi-weekly basis, which makes follow-up for distress an attainable goal and process for medical providers. However, for patients in the remission phase, this process can be more difficult as these individuals are seen months at a time, or at times, once or twice a year. Therefore, alleviating distress throughout all phases of cancer can be managed to a greater extent in the earlier phases of diagnosis and treatment and become difficult as visits and overall communication decrease in the later phases of the disease throughout observation and remission.

**Other Disease Burden.** Comorbid illness plays an essential, but poorly defined role in the diagnosis and management of hematological malignant diseases. In recent years, the direct influence of comorbid illness on treatment decision-making and survival outcomes has been documented for a variety of other malignancies including bladder, lung, head and neck, colorectal, breast, and prostate cancers (Hall, Ramanathan, Narayan, Jani, & Vijayakumar, 2004). Thus, the importance of measuring comorbidity in consistent and quantifiable ways needs to be recognized for hematological malignancies, as well.
Overall, the Charlson comorbidity index is intuitive, requiring users to select a condition from a defined list, rather than searching for disease value or specific information about disease severity. Identified conditions, depending upon the severity, possibly have an effect on the level of distress of the patient aside from the hematological malignancy. Therefore, the utility of the Charlson comorbidity index can be utilized as follow-up by a provider as the index score and presence of another disease can be a factor associated with distress of the patient.

**Discussion**

A total of 192 patients participated in the study within the 6 month data collection period. Of these 192 patients, a total of 41 individuals (21%) were identified as having a medical history of psychological distress. However, numerical data collected from both the DT and HADS measurement tools indicated a greater number than through medical record examination. Results from the DT indicated that 33% (N=64) of hematological patients were burdened by distress along with the HADS indicating that 31% (N=59) of patients reported scores of 8 or greater for anxiety, depression, or both. Therefore, these rates suggest the need for general acceptance of routine screening for distress as part of clinical care and further indicate the need for considerable progress towards distress management.

This study identified distress and factors associated with the greatest amount of distress amongst hematological patients and highlighted several areas where progress in implementing distress management has been limited. First and foremost is the fact that the Gundersen Lutheran Center for Cancer and Blood Disorders does not currently screen for distress on a routine basis with the hematological patient base. A second concern relates to methods used to identify distressed patients. Among the providers, many rely solely on interviews for indentifying distressed patients. These interviews are not standardized and have not been
systematically evaluated and thus, their sensitivity and specificity in indentifying distressed patients are unknown. In contrast, several studies (Hoffman, Jacobsen, Akizuki, & Ransom) have evaluated brief screening measures such as the Distress Thermometer and Hospital Anxiety and Depression Scale for their usefulness and efficiency in indentifying clinically significant distress, and objective procedures have been established to classify patients as distressed based on their self-reports.

Results of the current study suggest several future directions for examining implementation of distress management within the Gundersen Lutheran Center for Cancer and Blood Disorders. Results also identify the need to explore ways to promote greater screenings for all hematological patients for distress as indications that insufficient, as well as, inefficient resources are available. Ways to reduce the personnel and effort required to conduct screenings must be explored. Greater implementation may also be facilitated by stronger evidence that better results occur in alleviating distress when distress measurement tools and routine guideline assessments are utilized. Thus, further research needs to be conducted as currently much evidence supporting distress management is based on clinical experience.

Studies are needed to test the hypothesis that care delivered in a manner consistent with distress measurement tools and guidelines results in better control and eventual alleviation of distress. Evidence to support distress management among hematological patients could encourage many cancer care institutions that have lagged in implementing distress management guidelines to reorganize their routine care to be consistent with an approach that yield better distress alleviation outcomes.
CHAPTER V

CONCLUSION

Conclusions

According to the NCCN (2007), up to half of all adults with cancer experience clinically significant psychological distress and much of this distress goes unrecognized and untreated. Heightened distress has been shown to be associated with dissatisfaction with care, less adherence with care, and poorer quality of life (NCCN, 2007). Therefore, this study characterizes the need for establishment of a treatment model that attempts to encourage and engage practitioners by providing support, resources, and guidance towards alleviating distress.

Medical practices such as the Gundersen Lutheran Center for Cancer and Blood Disorders, need to seek to amplify the psychosocial care they provide to their patients and utilize models of distress care consistent with clinical practice guidelines to guide them. With this said, immense differences in size and organizational structure exist among outpatient hematologic practices. The variety of differences among various outpatient hematologic practices has made it difficult to create a universal standard of distress care, thus, leaving an inadequate single care model to be utilized by physicians. Furthermore, the availability of psychosocial professionals can vary significantly amongst practices and is another factor to consider when implementing clinical practice distress guidelines. Along with providing models of care, practices also need guidance on how to implement these models and learn how to maintain the changes they make within the organization and delivery of psychosocial care to their patients.
There is growing momentum to expand and improve distress care for patients with a hematological malignancy. Recent developments of quality distress care in hematology-related settings hold the promise of providing medical providers with information and overall knowledge useful in evaluating the care for distress their patients receive and indentifying the need for alleviating the distress. Therefore, the next step will be to develop and evaluate methods for improving the quality of distress care that are effective, efficient, and can be utilized as useful models for cancer care practices seeking to deliver care consistent with clinical practice guidelines for distress management.

**Recommendations**

In addressing the three research questions, many demographic factors were addressed. Of these demographic factors, marital status, sex, co-morbidity, and phase of disease were factors that produced varying results regarding the relationships and other diseases and impact on levels of distress a patient endures when dealing with a hematological malignancy. Therefore, a first recommendation from this study would be to conduct future research specifically pertaining to distress and related to these specific demographic factors for patients with a hematological malignancy. This would allow for a wider array of comparable literature regarding specific factors and level of distress in patients with a hematological malignancy, an aspect unattainable when preparing results for this study. Along with addressing these demographics, it is recommended that a future study incorporates ethnicity and socioeconomic status (SES) in order to further address specific factors that may be associated with distress levels of hematological patients.

A second recommendation would be the addition of the Distress Thermometer, Hospital Anxiety and Depression Scale or both to the consultation visit. Consultation visits consist
primarily of obtaining vital signs and addressing the current state of patients regarding their cancer, such as procedures throughout the diagnosis phase and reactions to their treatment. However, a reaction or side effect not regularly addressed during these visits pertains to the mental stability and distress of the patient. Most clinicians in cancer care do not use screening instruments for identifying distress in patients routinely due to the workload pressure they face (Mitchell, 2007). In one survey of medical staff, 50% never used a screening tool to assess distress (Mitchell, 2007). Similarly, in a survey of 123 mixed cancer professionals, 64% relied on clinical skills alone to detect depression and 8% routinely used a screening tool to detect a mood disorder or distress (Mitchell, 2007).

Patients in the diagnosis and treatment phases deal with a substantial amount of distress due to the unknown variables of the disease and changes within their lifestyle (e.g., work responsibility, social events, daily routine). Therefore, with consistent distress issues included in a weekly or bi-weekly consultation visit via a screening instrument, the medical provider can grasp a generalization of a patient’s current distress level and what to look for in the future in order to prevent distress altogether.

A third recommendation would be a survivorship program for individuals in remission as study results indicated distress within this patient group, as well. A survivorship program would enable patients in the remission phase to maintain their ‘safety net’ with medical attention or concerns that arise in the transition from patient to survivor with the aid of a health educator. Additionally, these individuals could maintain a strong support group by addressing concerns with the health educator who could provide resources and informational sessions that aid in addressing distress and ways to alleviate it. Furthermore, the health educator would be able to uplift others by creating a positive and less distressed environment as survivors would be
surrounded by their peers dealing with the same situation. Overall, they could become more knowledgeable about their current situation and the benefits that await them for the future. Understanding the amount of time it takes to fully embark upon the life had before cancer is crucial during this time and a health educator could fulfill a gratifying role in getting survivors back to where they want to be in their daily routine. Finally, a survivorship program would also allow for a patient’s security of knowing that a medical provider is accessible more often than a few times a year, which could possibly decrease distress as well. All in all, a survivor could attain a greater sense of ease as it is realized they have reduced contact with a provider and the medical care realm in general when transitioning back into their daily lifestyle.

Along with the implementation of a survivorship program, programs for individuals in other phases of a hematological malignancy are important, as well. As the study indicated, patients in the observational phase dealt with a significant degree of distress. With this said, educational and informational sessions for patients amongst their peers also could be beneficial for patients dealing with chronic lymphocytic leukemia and the ‘watchful waiting’ that accompanies this disease throughout the early stages. As patients attend these sessions, individuals who comprise a support group for the patient need to be recognized, as well. Therefore, the health educator could also conduct support sessions for individuals who care for those with cancer. These sessions can educate caregivers about the disease, aid in a better understanding of what the patient is going through and what to expect for the future, and most importantly, allow time for these valued persons to be amongst others who deal with similar situations and are striving for a critical knowledge-base of the malignancy also.

A final recommendation would be the systematic inclusion of the Charlson comorbidity index in order to help differentiate between the distress caused by other diseases and the level
caused by the hematological malignancy. Furthermore, this could enable the provider to specifically address and alleviate distress pertaining primarily to the hematological malignancy while encouraging an overall awareness of the prevalence of other diseases.

Limitations

In addition to addressing recommendations, limitations must be addressed. Other research has demonstrated differences in ethnic groups regarding cancer; therefore, an important limitation of this study is that few minority participants were included in the sample. From these known disparities in the cancer realm, results of the present study most likely would not be generalizable to a more ethnically diverse group of patients with multiple myeloma, chronic lymphocytic leukemia, Hodgkin’s lymphoma, or non-Hodgkin’s lymphoma. Furthermore, the sample attained for this study is considered a convenience sample as patients with a hematological malignancy arrived for scheduled appointments with their provider, rather than a random probability sample.

Additionally, this study was delimited to patients with a diagnosis of multiple myeloma, chronic lymphocytic leukemia, Hodgkin’s lymphoma, or non-Hodgkin’s lymphoma. While other researchers or cancer care professionals may be able to generally compare the results of this study to others patients seen with a hematological malignancy, the comparison of these results to levels of distress in patients with any type of malignancy may not be appropriate.

Thirdly, throughout the extent of this study, it was unknown as to how many patients would be seen daily, weekly, or monthly for a hematological malignancy at the Gundersen Lutheran Center for Cancer and Blood Disorders, especially within the four categories chosen for the study as this was affected by the cancellation and/or rescheduling of appointments.
Therefore, based upon differences in patient populations, distinctions in distress guidelines may be necessitated.

Finally, social desirability could certainly be a limitation. Many patients want the primary focus of their care to pertain to the cancer and its treatment. However, distress affects the emotional and psychological health of a patient, as well. Distress cannot be alleviated effectively if a patient desires to be compliant only towards the cancer and not towards another aspect, such as distress, that impact during the course of treatment and thereafter.

**Summary**

There is growing momentum to expand and improve psychosocial care for patients with a hematological malignancy. The recent development of quality indicators for psychosocial care in cancer care settings holds the promise of providing practitioners with information useful in evaluating the psychosocial care their patients receive and in identifying the need for quality improvement efforts. The next step will be to develop and evaluate methods for improving the quality of psychosocial care that are practical and effective and can serve as useful models for practices seeking to deliver care in a manner consistent with clinical practice guidelines for distress management.

All in all, empirical investigations examining psychosocial distress and need for care of patients with hematological malignancies are rare. Little is known about the use of psychotherapeutic intervention in routine care even though depression, anxiety, and overall distress are common during the course of cancer. Therefore, with proper implementation of this study, appropriate information about psychosocial services and provision of appropriate care will be provided at the Gundersen Lutheran Center for Cancer and Blood Disorders. To the degree
possible, these findings have the potential for serving as a foundation for other cancer centers along with further research in relation to this study and its demographics.
REFERENCES


Sherman, A., Simonton, S., Latif, U., Spohn, R., & Tricot, G. Psychosocial Adjustment and Quality of Life Among Multiple Myeloma Patients Undergoing Evaluation for


APPENDIX A

PATIENT PACKET MATERIALS
CONSENT FORM

WHAT IS INFORMED CONSENT?

Before you can make a decision whether to participate, you should understand your role in the study, including any possible risks and benefits associated with your participation in this study. This process is known as informed consent, and means that you will:

- Receive information about this study, including what information we are collecting, who will have access to that information and how we intend to use your information;
- Be asked to read, sign, and date this informed consent, if you agree to participate. If you don't understand something about the study or if you have questions, please ask for an explanation before you sign this form;
- Be given a copy of this form to keep; and
- Be able to withdraw from the study, if you decide at a later time that you do not want to participate.

PURPOSE:

Physicians at the Gundersen Lutheran Center for Cancer and Blood Disorders are interested in determining and comparing the stress levels of patients suffering from Hodgkin Lymphoma, Non-Hodgkin Lymphoma, Chronic Lymphocytic Leukemia and Multiple Myeloma.

If your stress level is high, your physician may immediately use the information to recommend some type of intervention such as counseling to help lower your stress levels.

BACKGROUND:

You are coming to Gundersen Lutheran's Center for Cancer and Blood Disorders to be treated for a Hodgkin Lymphoma, Non-Hodgkin Lymphoma, Chronic Lymphocytic Leukemia and Multiple Myeloma. You are being asked to participate in this study. The goal of this study is to assess the amount of stress in patients with Hodgkin Lymphoma, Non-Hodgkin Lymphoma, Chronic Lymphocytic Leukemia and Multiple Myeloma. The goal of this six-month outpatient study is to enhance our understanding of current stress levels, as well as compare the stress levels of patients with Hodgkin Lymphoma, Non-Hodgkin Lymphoma, Chronic Lymphocytic Leukemia and Multiple Myeloma.
Myeloma on the basis of age, gender, distance from the hospital, living arrangements, marital status, race, history of depression or anxiety, and progress and type of treatment. Psychosocial stress is common in patients with hematological malignancies because of many issues such as the threat to life, the need for episodic and/or aggressive treatment, and dealing with acute and/or uncomfortable symptoms. There is a lack of information regarding stress levels of patients suffering from Hodgkin Lymphoma, Non-Hodgkin Lymphoma, Chronic Lymphocytic Leukemia and Multiple Myeloma. The aim of this study is to discover and compare the level of stress in these patients.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

Approximately 150 patients being seen at Gundersen Lutheran's Center for Cancer and Blood Disorders will participate in this research study.

STUDY PROCEDURES:

This study has one component in which you may participate. If you agree to participate, you will fill out 2 surveys (stress and HADS) at today's doctor visit. A member of Gundersen Lutheran's study team will collect information from your medical records about your medical history, and your medical care.

The study looks at your stress survey, type of hematological disorder, age, gender, distance from the hospital, living arrangement, race, history of depression or anxiety, where you are in the treatment process, and the type of treatment you receive.

Your physician will see the survey at your appointment. If he/she determines that you have a high level of stress, he/she will discuss ways to lower your stress level. It may be recommended that you see a specialist to discuss your stress.

RISKS OF PARTICIPATION:

This is an observational study and will require you to respond to a stress and HADS survey at this time. There are no physical risks associated with this study. There are no costs to you for participating. The principal way that this study will affect you is by donating your time to complete the surveys.

If you are found to be highly distressed, your physician may intervene to help lower your stress level.

You will be informed, within a reasonable amount of time, of any new information that becomes available that may affect your willingness to continue participating in this study.
**BENEFITS OF PARTICIPATION:**

You may not receive any personal benefits from taking part aside from assistance with lowering stress levels, but we hope that this study will help physicians understand how much stress their patients are under.

**ALTERNATIVE TREATMENTS:**

This is an observational study so there is no alternative treatment.

**WHAT ARE THE COSTS?**

You will not be paid for participating in this study. Taking part in this study will not add to your medical care costs.

**RIGHTS AS A STUDY PARTICIPANT:**

You may choose not to be in the study, or, if you agree to be in the study, you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your access to health care at Gundersen Lutheran. If you do decide to withdraw, we ask that you contact the Principle Investigator of this study, Craig Cole, MD, in writing and let him know that you are withdrawing from the study. After you withdraw, the data previously collected about you still will be used in the study, but no new data about you will be collected for study purposes.

**HOW WILL INFORMATION BE KEPT PRIVATE?**

Researchers will keep your personal information as private as possible. Researchers cannot guarantee absolute privacy. Your personal information may be disclosed if required by law. Your research records will include things such as your medical history, results of your exams, reports from your surgery and treatment, and reports of your office visits. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include the local Institutional Review Board (An institutional review board (IRB) is a group of health care professionals and community members who review research studies to protect the rights and welfare of research participants).

**WHO TO CALL FOR QUESTIONS OR PROBLEMS:**

Questions regarding the research study and your participation should be directed to the Principal Investigator, Craig Cole, MD, at (608) 782-7300 – office hours 8am – 5pm.
For questions about your rights as a research participant, you may contact Bud Hammes, PhD, Chairperson of the Gundersen Clinic, Ltd. Institutional Review Board at (608) 782-7300 or 1-800-362-9567

SIGNATURES:

I have read all the above, asked questions and received answers concerning areas I did not understand. I have had the opportunity to take this consent form home for review and/or discussion.

I willingly give my consent to participate in this program. Upon signing this form, I will receive a copy. I may also request a copy of the protocol (full study plan).

__________________________________________   ____________
Patient signature (or legal representative)      Date

__________________________________________   ____________
Physician signature                           Date
Welcome!

Your satisfaction and well-being are important to us. In order to improve this, we would like to ask you some questions about the level of stress you experience as a patient with a blood disorder.

With this survey, we are trying to determine how much stress you are under and which factors cause the most distress when you come to the Center for Cancer and Blood Disorders. Knowing this information will help us make your experience less stressful. We have attached a consent form for you to read and sign, as well as, a survey to fill out. A copy of the consent form will be mailed to you for reference after your visit.

If you have any questions or medical concerns, please feel free to call the Hematology Department at Gundersen Lutheran at (608) 782-7300 at extension 50139.

Thank you for your time.

Sincerely,

Gundersen Lutheran Hematology Staff
Dear,

Thank you for your recent participation in the distress study conducted by the Hematology staff at the Gundersen Lutheran Center for Cancer and Blood Disorders. Your time has been a valued asset towards achieving significant results for the study and aids in helping us attain a provision of quality care at your visits. Your satisfaction and well-being are important to us.

Enclosed is a copy of the consent form for you to keep for your records as a participant in the distress study. Please use this as a reference if questions arise. If you have any questions or medical concerns, please feel free to call the Hematology Department at Gundersen Lutheran at (608) 782-7300 at extension 50139.

Thank you for your time in this effort towards patient care.

Sincerely,

Gundersen Lutheran Hematology Staff
APPENDIX B

MEASUREMENT TOOLS
Hospital Anxiety and Depression Scale (HADS)

Patients are asked to choose one response from the four given for each interview. They should give an immediate response and be dissuaded from thinking too long about their answers. The questions relating to anxiety are marked "A", and to depression "D". The score for each answer is given in the right column. Instruct the patient to answer how it currently describes their feelings.

<table>
<thead>
<tr>
<th>A</th>
<th>I feel tense or 'wound up':</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Most of the time</td>
</tr>
<tr>
<td></td>
<td>A lot of the time</td>
</tr>
<tr>
<td></td>
<td>From time to time, occasionally</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D</th>
<th>I still enjoy the things I used to enjoy:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Definitely as much</td>
</tr>
<tr>
<td></td>
<td>Not quite so much</td>
</tr>
<tr>
<td></td>
<td>Only a little</td>
</tr>
<tr>
<td></td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A</th>
<th>I get a sort of frightened feeling as if something awful is about to happen:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very definitely and quite badly</td>
<td>3</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>2</td>
</tr>
<tr>
<td>A little, but it doesn't worry me</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things:</th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I always could</td>
</tr>
<tr>
<td>Not quite so much now</td>
</tr>
<tr>
<td>Definitely not so much now</td>
</tr>
<tr>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind:</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal of the time</td>
</tr>
<tr>
<td>A lot of the time</td>
</tr>
<tr>
<td>From time to time, but not too often</td>
</tr>
<tr>
<td>Only occasionally</td>
</tr>
</tbody>
</table>
### D I feel cheerful:

<table>
<thead>
<tr>
<th>Option</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>3</td>
</tr>
<tr>
<td>Not often</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Most of the time</td>
<td>0</td>
</tr>
</tbody>
</table>

### A I can sit at ease and feel relaxed:

<table>
<thead>
<tr>
<th>Option</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>0</td>
</tr>
<tr>
<td>Usually</td>
<td>1</td>
</tr>
<tr>
<td>Not Often</td>
<td>2</td>
</tr>
<tr>
<td>Not at all</td>
<td>3</td>
</tr>
</tbody>
</table>

### D I feel as if I am slowed down:

<table>
<thead>
<tr>
<th>Option</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nearly all the time</td>
<td>3</td>
</tr>
<tr>
<td>Very often</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
</tbody>
</table>

### A I get a sort of frightened feeling
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>like 'butterflies' in the stomach:</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>Occasionally</td>
<td>1</td>
</tr>
<tr>
<td>Quite Often</td>
<td>2</td>
</tr>
<tr>
<td>Very Often</td>
<td>3</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I have lost interest in my appearance:</td>
<td></td>
</tr>
<tr>
<td>Definitely</td>
<td>3</td>
</tr>
<tr>
<td>I don't take as much care as I should</td>
<td>2</td>
</tr>
<tr>
<td>I may not take quite as much care</td>
<td>1</td>
</tr>
<tr>
<td>I take just as much care as ever</td>
<td>0</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel restless as I have to be on the move:</td>
<td></td>
</tr>
<tr>
<td>Very much indeed</td>
<td>3</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>2</td>
</tr>
<tr>
<td>Not very much</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>I look forward with enjoyment to things:</td>
</tr>
<tr>
<td>---</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td></td>
<td>As much as I ever did</td>
</tr>
<tr>
<td></td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td></td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td></td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I get sudden feelings of panic:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very often indeed</td>
</tr>
<tr>
<td></td>
<td>Quite often</td>
</tr>
<tr>
<td></td>
<td>Not very often</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I can enjoy a good book or radio or TV program:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Often</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
</tr>
<tr>
<td></td>
<td>Not often</td>
</tr>
<tr>
<td></td>
<td>Very seldom</td>
</tr>
</tbody>
</table>
Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression.

<table>
<thead>
<tr>
<th>Score Range</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-7</td>
<td>Normal</td>
</tr>
<tr>
<td>8-10</td>
<td>Borderline abnormal</td>
</tr>
<tr>
<td>11-21</td>
<td>Abnormal</td>
</tr>
</tbody>
</table>

Reference:

Zigmond and Snaith (1983)