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Chapter I

Review of the Literature

An Explanation of Bone Marrow Transplantation

Over the past 40 years, bone marrow transplantation (BMT) has been employed with increasing frequency, and success, to treat numerous diseases. After World War II, fears of nuclear warfare inspired interest in the effects of radiation on the human body. In studies using animals, researchers discovered bone marrow was the organ most sensitive to the harmful effects of radiation. As a result, researchers identified marrow reinfusion as a cure for lethally irradiated animals. In the 1950s people were given lethal doses of radiation in an attempt to treat Leukemia, but people still died even after a BMT. During the 1950s and 1960s, almost 200 BMTs were performed in humans without long-term success. However, transplantation using identical twins enjoyed more success and provided a foundation for further research (Andrykowski, 1994a; 1994b; Moore, 2008).

The most important cell needed for BMTs is the hematopoietic stem cell, which can be located in bone marrow, cord blood, or peripheral blood. When an individual uses his/her own cells for transplant it is referred to as an autologous transplant. When the cells are obtained from someone other than the recipient, it is referred to as an allogeneic transplant. In 1968, the first successful allogeneic transplantation saved the life of an infant with X-linked lymphopenic immune deficiency as well as another with Wiskott-Aldrich syndrome. Successful transplantations for individuals diagnosed with Aplastic Anemia, and later for those diagnosed with Leukemia followed. BMT now offers a possible life-long cure for those with malignant
diseases of the blood or lymph nodes including: Acute Lymphoblastic Leukemia (ALL), Acute Myelogenous Leukemia (AML), Chronic Myelogenous Leukemia (CML), Juvenile Myelomonocytic Leukemia, Myelodysplastic Syndromes, Plasma Cell Disorders, and Hodgkin and non-Hodgkin Lymphoma, as well as other nonmalignant diseases (Andrykowski, 1994a; 1994b; Moore, 2008).

Advances in histocompatibility testing (i.e., the process of determining the compatibility of the antigens of the donor and recipient before transplantation) and the development of marrow donor registries, such as the National Marrow Donor Program (NMDP), facilitated the use of unrelated donors in BMT and expanded the number of patients who can successfully receive transplants. An allogeneic MBT is termed “syngeneic” when the cells are obtained from an identical twin, “related” when the donor and recipient are related, and “unrelated” when the donor and recipient are not related. Some diseases can be treated with an autologous transplant; whereas other diseases must be treated with an allogeneic transplant. In general, autologous transplants are less threatening than allogeneic transplants because recipients of their own cells do not share the risk of contracting Graft-versus-Host Disease (GVH), which occurs when the new immune system begins to attack the patient’s body. GVH generally involves the skin, liver, and gastrointestinal tract and puts the patient at an increased risk for infection and death (Moore, 2008).

The process of BMT can engender a great deal of emotional and physical distress in patients as well as their families. BMT generally occurs after traditional chemotherapy regimens have been attempted and failed, resulting in a relapse of the cancer. After undergoing numerous health screenings and a psychological evaluation, patients who qualify for BMT are hospitalized for approximately one month. During hospitalization, patients endure lethal doses of
chemotherapy, and sometimes radiation therapy, with hope of destroying the cancer cells. During treatment, the patient’s immune system, which resides in the bone marrow, is severely compromised. For this reason, it is necessary to infuse patients who received high doses of chemotherapy with clean bone marrow.

Because patients’ immune systems are compromised, they are required to stay on the hospital’s bone marrow transplant unit the entire time they are hospitalized, but visitors are allowed. If patients contract infections, they must stay in their rooms and are not allowed to walk around the unit until the infection is cured. Patients may find themselves bored, lonely and homesick during this time of isolation; with additional time alone with their thoughts, they may contemplate the uncertainty of treatment outcome unsettling. In addition, many patients may have difficulty sleeping in a strange bed with nurses entering their rooms at various times during the night to record their vital signs. The majority of patients experience some physical complications such as mucositis (i.e., painful mouth sores caused by chemotherapy), nausea, pain, fevers, and other infections. In addition, patients may feel overwhelmed by the large volume of information they have received regarding their health and treatment and may feel a loss of control over their future and bodies (Lesko, 1994; Stewart, & Sugar, 2002).

**NCCN Introductory Information**

Leading institutions such as the National Comprehensive Cancer Network (NCCN) recognize psychological distress as a significant concern for individuals with cancer. Because a diagnosis of cancer is physically stressful and emotionally taxing for patients and their support networks, the NCCN (1999) strongly recommends routine assessment of distress for all oncology patients. The word distress was chosen by the NCCN Distress Management Panel to represent the emotional concerns of cancer patients because it carries less stigma than other commonly
used words that allude to potential mental health issues or illness, such as psychiatric, psychosocial, and emotional. In addition, the panel believed the term “distress” sounded “normal,” and could be defined and measured by self-report (Holland, & Bultz, 2007). Distress is defined by the NCCN Distress Management Panel (2010) as

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. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis (Holland et al., p. 3).

The (NCCN) acknowledges the importance of assessing distress in cancer patients and convened a panel of representatives from all major disciplines involved in the care of patients with cancer (i.e., oncologists, nurses, psychiatrists, psychologists, chaplains, social workers, and patient advocates) to formulate clinical practice guidelines regarding distress management which are updated annually (Holland & Bultz, 2007; NCCN, 1999). In 2003, the NCCN Distress Management Panel published more fully developed principles for psychosocial care and distress management establishing for the first time a set of quality measures for assessing and managing distress (Holland & Bultz, 2007). Based on these standards, Holland, Greenberg and Hughes (2006) published a handbook to guide clinicians in managing psychiatric and psychosocial challenges associated with cancer.

NCCN Assessment Guidelines

NCCN guidelines stipulate that all patients should be screened for distress at their initial office visit and appropriate subsequent intervals. In addition, mental health professionals with experience in managing the psychosocial aspects of cancer should be available to patients (Holland et al., 2010). As recommended, the initial step in managing distress is administering a self-report measure, such as the Distress Thermometer (Roth, Kornblith, Batel-Copel, Peabody,
Scher, & Holland, 1998). Based on the initial assessment, a clinical decision should then be made regarding the severity of the patient’s distress. Patients enduring moderate to severe distress should be referred to a mental health professional, social worker, and/or for pastoral services, as appropriate. For patients experiencing mild distress continued observation by the primary oncology team is considered appropriate (Holland et al., 2010).

It is reasonable to expect people with cancer diagnoses to experience some level of distress throughout illness and treatment. Routine assessment at all stages of disease is needed to determine at what point distress levels become intolerable and require the attention of mental health professionals. Distress may range from expected fears, worry, and sadness to more severe problems, such as clinical depression, generalized anxiety disorder, panic disorder, isolation, and/or spiritual crisis (Holland & Bultz, 2007). However, not all institutions follow NCCN guidelines to routinely screen all cancer patients for distress.

A recent survey reported eight out of 15 (53%) NCCN member institutions conducted a routine distress screening for at least some of their patients, many of whom were currently undergoing BMT (Jacobsen & Ransom, 2007). However, all but one of the institutions considered routine screening an important aspect of clinical care. Of the remaining six institutions not screening patients for distress, two stated they either did not have enough resources to screen and/or they did not have enough resources to see distressed patients who might be identified. Four institutions indicated they were in the process of piloting procedures for routine distress screening. Of those conducting routine screenings, 37.5% used an interview, and 25% a self-report measure; 37.5% utilized both a self-report measure and an interview. Considering the interview is not standardized and has not been systematically evaluated, its ability to detect distressed patients may be unreliable. It is also concerning that only 20% of the
sampled institutions reported screening all patients for distress, as is recommended by the NCCN guidelines. Of those institutions utilizing a self-report measure, 60% employed the Distress Thermometer (Jacobsen & Ransom, 2007).

Although the sample size for this study was small, the results are indicative of the need for additional professionals to provide routine screenings for distress in more institutions. In addition, Jacobsen and Ransom (2007) suggested attempts should be made to reduce the effort required to conduct screenings. This would likely be accomplished through the use of simple face valid measures that require minimal time for completion and interpretation, such as will be developed and validated in this study.

**High Levels of Distress among Cancer Patients**

High levels of distress are common among cancer patients (Hoffman, Zevon, D’Arrigo, & Cecchini, 2004; Jacobsen et al., 2005; Trask et al., 2002). One third to over one half of cancer patients report significant distress (Carlson et al., 2004; Lee et al., 2005; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001), whereas fewer than 10% of these patients are referred for professional psychosocial care (Carlson & Bultz, 2003). In a large scale study, Zabora et al. (2001) assessed 4496 patients with various cancer diagnoses using the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983), a 53-item measure of psychological distress containing three global scales and nine subscales. For the purposes of this study, a BSI Global Severity Index (GSI) score was calculated to identify a person’s general level of distress during the past seven days. An elevation of two or more subscales resulting in a GSI score of 63 or above indicated the patient was experiencing a significant level of distress. Although not designed for use with cancer patients, Zabora et al. (2001) contend the measure is commonly used among medical and psychiatric populations and is therefore an appropriate measure for use
with cancer patients. Zabora et al. (2001) concluded that the overall prevalence of distress for this sample was 35.1%. Their results support the necessity of screening patients to identify those who are experiencing significant distress to best provide early intervention.

**Detection of Distress**

Unfortunately, evidence indicates distress is often not recognized by oncology professionals, and thus patients are not referred to psychosocial professionals for treatment. Fallowfield et al. (2001) examined the ability of 143 physicians to determine the psychological status of 2297 cancer patients during outpatient consultations. The authors concluded physicians made an inaccurate assessment for 797 patients based on the results of the General Health Questionnaire (Goldberg & Williams, 1988) completed prior to a video-taped consultation with the physicians.

In another study, Sollner et al. (2001) examined the ability of oncologists to accurately determine patients’ need for referral for psychosocial counseling and support. Sollner et al. (2001) asked eight oncologists to estimate the level of distress, need for psychosocial support, and desire for counseling of 298 cancer patients undergoing radiotherapy. Oncologists recognized the presence of severe distress in only 11 of the 30 severely distressed patients in the sample as determined by patients’ responses on numerous screening measures. Oncologists were frequently unable to accurately perceive the patients’ level of social support and their recommendations for counseling did not correlate with patient distress or their perceived level of support. Instead, patients whose need for psychosocial support and counseling were missed by oncologists suffered more often from progressive disease and exhibited more denial behaviors than patients whose needs were accurately perceived or overestimated by oncologists. Muriel et al. (2009) reported that oncologists estimated over one-third of patients experienced
psychological distress; however, only about 50% had mental health services affiliated with their practice. Forty-seven percent reported providing a referral for psychosocial services, whereas 48% reported providing a referral and a prescription for psychotropic medications, primarily selective serotonin reuptake inhibitors and benzodiazepines.

Alternatively, patients are often unwilling to express increased levels of distress or need for psychosocial care due to fear of being stigmatized as weak or a cowardly patient. Holland, Kelly, and Weinberger (2010) explained that cancer patients are often held responsible for their survival in a way that other patients are not, due to a prevailing belief that positive thinking can control the outcome of the illness. This leads patients to believe that they must always be brave and avoid talking about issues of concern, such as psychological distress. Medical staff and patients may also believe that high levels of anxiety and depression are normal and expected reactions to cancer; consequently, they are not referred for appropriate psychosocial care. Unfortunately, it is often patients with the highest levels of distress, the least social support, lower levels of illness knowledge, and more avoidant coping styles who are the least likely to have interest in, or accept, psychosocial care. Yet, they are the most likely to benefit from treatment (Holland et al., 2010; Merckaert, Libert, Messin, Milani, Slachmuylder, & Razavi, 2010). Holland et al. (2010) suggest there is a universal need for information regarding cancer and its consequence; information about distress and available psychosocial treatments should be provided to reduce the associated stigma.
Individual Differences in Distress

There may also be individual differences in levels of distress among cancer patients. Jacobsen et al. (2005) found that women were significantly more likely to score at or above the cutoff score for a significant level of distress. Similarly, patients with a poorer performance status, as indicated by participant responses on the Karnofsky Performance Scale (Wingard, Curbow, Baker, & Piantadosi, 1991), were significantly more likely to be considerably distressed. As expected, patients who scored at or above the cutoff score for clinically significant levels of distress were more likely to report various practical, familial, emotional, and physical problems and concerns.

In another study, Carlson et al. (2004) reported 37.8% of patients with various cancer diagnoses met criteria for clinical levels of distress. There were no gender differences in levels of anxiety or overall levels of distress. Conversely, a higher proportion of men than women met criteria for somatization and more women than men met criteria for depression, indicating women may be more likely to experience emotional difficulties during illness. Minorities, patients with lower incomes, and those currently undergoing cancer treatments were more likely to experience distress. Also, younger patients struggled significantly more than older patients. Carlson et al. (2004) indicated that previous researchers theorized younger patients may struggle with higher baseline levels of distress due to a larger disruption in social and familial roles such as raising children and establishing careers. In addition, it may be viewed as more unfair that a younger person be forced to cope with cancer than someone who has lived a longer life (Carlson & Bultz, 2002; Wenzel et al., 1999). It is also possible that historically disadvantaged groups such as minorities, women and those with lower incomes would report higher levels of distress
than the general population even when they are healthy; thus, patients with these characteristics may enter treatment with higher levels of distress than other patients.

**Characteristics of Distress**

Likely causes of increased distress levels among cancer patients include physical, emotional, social, practical, and spiritual concerns. Carlson et al. (2004) assessed the distress of cancer patients who entered the Tom Baker Cancer Centre for a variety of reasons (e.g., diagnosis, new patient consultation, treatment, follow-up) during a one-month time period using a cross-sectional methodology. Patients most frequently reported facing the following issues currently: fatigue, pain, managing unpleasant emotions or stress, depression, and anxiety; fatigue was the most commonly endorsed difficulty. Notably, this finding is consistent with other studies that recognized fatigue as one of the most significant and long-term difficulties associated with cancer and its treatment (Hann et al., 1997; Hann et al., 1999; Knobel et al., 2000; Neitzert et al., 1998).

In Carlson et al.’s (2004) study, well over half of the participants indicated they were aware of departments devoted to meeting the emotional and social needs of patients. Yet, almost half of patients who met criteria for distress did not seek professional psychosocial services, nor did they intend to in the future. The most popular reason for not utilizing available resources was the perception that aid was not necessary. Interestingly, very few participants indicated stigma as a reason for not seeking help. The results of this study speak to the necessity of not only screening patients for distress, but also making recommendations to appropriate sources of additional support (Carlson et al., 2004).
**Course of Distress**

Information about the trajectory of distress among cancer patients at different stages in the illness is crucial as increased levels of distress have been associated with poorer treatment adherence, decreased satisfaction with care, and poorer quality of life (Kennard et al., 2004; Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000; Von Essen, Larsson, Oberg, Sjoden, 2002). Past research indicates many BMT survivors develop psychosocial morbidity secondary to transplantation (Ell, Nishimoto, Morvay, Mantell, & Hamovitch, 1989; Ersek, 1992; Gaston-Johnson, 1996). Sutherland et al. (1997) compared BMT survivors with healthy individuals and found a significantly greater degree of impaired overall health, social functioning, and emotional well-being in those who had received a transplant. Survivors may experience on-going feelings of isolation and loneliness, fear of death, a loss of personal control, depression, and suicidal ideation (Belec, 1992; Ersek, 1992; Lesko, 1994; Molassiotis & Morris, 1997). Physical pain and psychological distress during transplantation may precipitate and further aggravate these later problems (Fife et al., 2000). In addition, there is evidence to suggest psychosocial variables such as depression and social support may affect the outcome of the BMT as well as survival (Andrykowski, Brady, & Downey, 1989). Appropriately, quality of life is generally regarded as a mark of BMT treatment effectiveness (Fife et al., 2000).

Despite considerable research supporting the importance of quality of life following BMT, few longitudinal studies have investigated the effect of psychosocial variables prior to and during BMT. Fife et al. (2000) investigated the specific times during BMT treatment in which patients experienced the greatest distress. In addition, they examined factors associated with distress and the patient’s ability to successfully cope. Fife et al. (2000) also investigated the variables that indicated patients were in the greatest need of intervention in an attempt to
minimize or prevent emotional and social problems secondary to transplantation. Participants included 101 patients being treated with either autologous or allogeneic bone marrow transplants who were recruited prior to hospitalization through convenience sampling. Data was collected through self-report measures at seven time points: before hospitalization, one or two days before infusion of bone marrow during the end of high-dose chemotherapy, seven days after bone marrow infusion, 14 days after infusion or just before hospital discharge, and one month, three months, and 12 months after hospital discharge. Fife et al. (2000) used the Bi-Polar Profile of Mood States (Lorr & McNair, 1988) to assess emotional response, whereas they measured the impact of BMT on patient perception of personal control over what is currently happening in their lives and what is likely to happen in the future using the Mastery Scale (Pearlin, Menaghan, Leiberman, & Mullan, 1981; Pearlin & Schooler, 1978). The impact of symptomatology was controlled for in the analysis using the BMT Symptom Checklist developed by the study’s research team.

Fife et al. (2000) found the period of greatest distress for patients occurred after hospital admission and before bone marrow infusion during which there was a significant increase in anxiety, depression, and uncertainty. This was the time of greatest emotional distress throughout hospitalization and the first year after transplantation. Both anxiety and uncertainty dropped significantly after discharge from the hospital. Physical symptoms increased from the first assessment period to the second, and further increased from the second assessment period to the third, despite the significant decline in depression and anxiety beginning one week after bone marrow infusion. There was a gradual decline in uncertainty and anger throughout hospitalization. The periods of lowest emotional distress were three and 12 months after BMT when patient response was significantly more positive than it had been at baseline.
In contrast, Molassiotis, Van Den Akker, Milligan, Goldman, & Boughton (1996) found high psychological morbidity was present the day before transplant, but remained elevated throughout hospitalization and a month after hospital discharge. Molassiotis et al. (1996) measured changes in the psychological status, self-esteem, dependence on others, physical symptom distress, and coping of 26 BMT patients during four time points: the day before transplant, 21 days after transplant, a few days before hospital discharge, and approximately one month after discharge from the hospital. They used the Profile of Mood Scale (McNair, Lorr, & Doppleman, 1971) and the Symptom Distress Scale (SDS; McCorkle & Young, 1978) to assess patient mood and level of distress; although, the SDS was utilized only at time three. Tension-anxiety and depression decreased throughout hospitalization although not significantly, while anger-hostility and fatigue increased, especially in the last assessment. The primary causes of distress included changes in bowel patterns, fatigue, insomnia, poor appetite, and poor concentration and were associated with greater mood disturbance. Patients who received professional psychological support during BMT reported significantly lower mood disturbance compared to patients who did not.

Meyers et al. (1994) found that 40% of BMT patients endorsed high levels of anxiety prior to transplantation; however, their anxiety decreased significantly during hospitalization. Patients’ anxiety also remained low during follow-up. They concluded the type of transplant, patient locus of control, and degree of social support were related to psychological distress during and after BMT. The results of Fife et al. (2000), Molassiotis et al. (1996), and Meyers et al.’s (1994) studies may have differed due to their distinct times of assessment and use of different measures to assess distress. Diverse samples may also have led to conflicting results.
Physical Issues and Psychological Distress

Another area of disagreement within past literature is the degree to which physical symptoms affect emotional distress during BMT, and conversely, the degree to which pre-transplant psychosocial variables may influence physical symptoms during BMT. As previously stated, Molassiotis et al. (1996) found distress caused by physical symptoms was related to mood disturbances, while Ho, Horne and Szer (2002) concluded pre-transplant psychosocial variables were not associated with pain intensity during hospitalization. Participants in a prospective longitudinal study by Ho et al. (2002) included 42 BMT patients. The authors investigated the relationship between pre-transplant psychosocial variables including the quality of family relationships and coping resources (i.e., cognitive, social, emotional, spiritual/philosophical, and physical) and psychophysiological outcomes during the immediate recuperative period (seven and 14 days post-transplant). Ho et al. (2002) assessed coping resources using the Coping Resources Inventory (Hammer & Marting, 1988). They measured psychological distress and pain intensity at seven days and 14 days after bone marrow infusion using the Brief Symptom Inventory (BSI; Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974) and by asking patients to indicate their level of pain on a scale from zero to 100. Whereas patients with more coping resources and those who exhibited health-promoting behaviors pre-transplant experienced better psychological adjustment during hospitalization, none of the psychological predictors of this study were related to the patients’ subjective levels of pain intensity. Instead, the type of transplant (allogeneic versus autologous) and conditioning regimen were associated with pain during the engraftment period with allogeneic patients reporting more pain than autologous patients.
In contrast to the findings of Ho et al. (2002), Fife et al. (2000) discovered few significant differences between those receiving allogeneic transplants and those receiving autologous transplants, with no significant differences on any variable for more than one time point. These results are similar to those of Jenkins, Linington, & Whittaker (1991), Somerfield and Curbow (1992), and Baker et al. (1994); all of which concluded there was no relationship between type of BMT and adjustment or physical symptomatology. Fife et al. (2000) found that, physical symptoms did not correlate with anxiety, depression, anger or uncertainty during transplantation; however, a high level of physical symptomatology 12 months after transplantation was significantly positively correlated with a higher level of emotional distress. Fife et al. (2000) instead concluded that the variable most strongly and consistently related to emotional response was personal control. In concordance with Fife et al. (2000), Baker, Marcellus, Zabora, Polland, and Jodrey (1997) also found that personal control, as measured by the Mastery Scale, along with dispositional optimism, was predictive of psychosocial adjustment.

Each of these studies add to the literature regarding distress among cancer patients, yet assessed distress from varied perspectives utilizing different predictive variables, assessments, and varying time points for assessment making them difficult to compare. As suggested by Fife et al. (2000), additional prospective longitudinal research is needed if effective intervention strategies addressing psychological, emotional, and social complications are to be implemented for patients undergoing BMT.
Religious/Spiritual Concerns and Psychological Distress

Researchers have recently become interested in the influence of religiosity and spirituality on health outcomes (Sherman, Simonton, Latif, Spohn, & Tricot, 2005). Although often used synonymously, it is important to note that spirituality differs from religiosity, with spirituality encompassing the beliefs advocated in organized religion but without the structure and institutional implications (Zinnbauer & Pargament, 2005). More broadly, spirituality includes one’s striving for meaning in life and connectedness (Girardin, 2000; Visser, Garssen, & Vingerhoets, 2010). Much of the past research investigating the influence of belief in a higher power has not made this distinction, as there is noticeably a great deal of overlap in the meanings of the two terms (Miller & Thoresen, 2003). This lack of distinction has led many researchers to use the terms religion and spirituality in conjunction with one another (Park, 2007).

Religion and spirituality can be valuable resources for individuals with cancer (Halstead & Fernsler, 1994; Sherman, Simonton, Adams, Vural, & Hanna, 2000), with some research indicating positive correlations between religiosity and enhanced coping, or more effective adjustment to illness (Harrison, Koenig, Hays, Emec-Akwari, & Pargament, 2001; Sherman & Simonton, 2001; Shuster, Steeves, Onega, & Richardson, 1996). As recognized by Pargament, Koenig, and Perez (2000), religious coping encompasses a wide display of responses to illness and stress, including efforts at meaning, control, comfort, and life transformation. While considerable difficulties exist in finding an optimal approach for assessing religiosity and spirituality in research studies, there has been a move toward understanding the functional aspects spirituality serves in the lives of patients rather than merely categorizing the effects of specific religious beliefs (Sherman & Plante, 2001). More specifically, researchers investigated
the ways in which patients’ religious involvement aids in coping with their illness (Sherman et al., 2005). As characterized by Pargament (2002),

Questions about the general efficacy of religion should give way to the more difficult but more appropriate question, "How helpful or harmful are particular forms of religious expression for particular people dealing with particular situations in particular social contexts according to particular criteria of helpfulness or harmfulness?" (p. 168) Individuals experience a wide array of religious and spiritual responses following a diagnosis of cancer ranging from spiritual conflicts and ambivalence to reassurance and comfort (Taylor, Outlaw, Bernardo, & Roy, 1999). As categorized by Pargament, Smith, Koenig, and Perez (1998), positive religious coping refers to a patient’s tendency to move closer to religious resources in response to a stressful situation whereas negative religious coping refers to a patient’s tendency to question, feel abandoned by, doubt, and move away from religiosity. For instance, positive coping strategies are likely to include: (1) religious purification/forgiveness (i.e., searching for cleansing through religious actions, such as asking for forgiveness for sins committed); (2) religious direction/conversion (i.e., looking to religion for a radical life change); (3) religious helping (i.e., attempting to provide spiritual support and comfort to others); (4) seeking support from clergy/congregation members; (5) collaborative religious coping (i.e., working together with God to solve problems); (6) religious focus (i.e., engaging in religious activities to divert attention); (7) active religious surrender (i.e., relinquishing control to God); (8) benevolent religious reappraisal (i.e., redefining a stressor as benevolent or potentially beneficial); (9) spiritual connection (i.e., experiencing a sense of connectedness with God or others); and (10) marking religious boundaries (i.e., clearly defining acceptable and unacceptable religious behavior).
Conversely, negative coping strategies are likely to include: (1) spiritual discontent (i.e., expressing confusion and dissatisfaction with God); (2) demonic reappraisal (i.e., defining a stressor as an act of the devil); (3) passive religious deferral (i.e., waiting for God to take control of the situation); (4) interpersonal religious discontent (i.e., expressing confusion and dissatisfaction with one's relationship with clergy or church); (5) reappraisal of God's powers (i.e., questioning the power of God); (6) reappraisal of God as punishing (i.e., assuming the stressor is a punishment from God); and (7) pleading for direct intercession/or a miracle from God (Ano & Vasconcelles, 2005; Pargament et al., 2000). As stated by Pargament et al. (2000), in research it is necessary to understand “how the individual is making use of religion to understand and deal with stressors” (p. 521). Interestingly, the potential negative aspects of religious conflict have received much less attention in research than the potential positive effects of religious coping (Sherman & Plante, 2001; Sherman et al., 2005).

Outside the scope of psychosocial oncology, some researchers have found a relationship between religiosity and psychological distress (Ai, Park, Huang, Rodgers, & Tice, 2007; Ano & Vasconcelles, 2005). Ai et al. (2007) examined the effect of preoperative religious coping styles on postoperative psychological distress in 309 cardiac patients, noting that although positive religious coping styles are related to favorable outcomes, the relationship is mediated by perceived social support and hope. Likewise, the relationship between negative religious coping styles and postoperative distress was mediated by low social support and hopelessness. The findings of Ai et al. (2007) provide evidence that there may be positive effects of religion on health outcomes; however, they may be indirect. Positive religious coping styles may provide patients with additional perceived social support and hope, which may in turn decrease psychological distress. Ano and Vasconcelles (2005), in a meta-analysis of 49 studies examining
the relationship between religious coping styles and psychological adjustment, emphasized that research regarding the efficacy of religious coping when people are dealing with stressful situations is mixed. However, their conclusions generally support the hypothesis that positive religious coping styles are related to positive psychological adjustment to stress, and negative religious coping styles are related to negative psychological adjustment to stress.

Although the exact pathways through which religious coping may affect psychological distress are not well understood, especially in such stressful events as cancer, some researchers (e.g., Exline, 2002; Hill & Pargament, 2003) suggest that intrapersonal and interpersonal religious struggles may lead to increased levels of distress in patients. A patient’s personal struggle with religious/spiritual beliefs could lead to diminished self-worth or perceived self-control. Interpersonal religious struggles may lead to weakened bonds with one’s spiritual community and God which may contribute to feelings of alienation and isolation. On the other hand, such spiritual struggles may eventually lead to personal growth via a reconciliation of faith or discovery of a new spiritual path (Koenig, Pargament, & Nielsen, 1998; Pargament, Koenig, & Perez, 2000).

Stefanek, McDonald, and Hess (2005) ascertain that studies investigating the impact of religion and spirituality on quality of life are “decidedly mixed,” with research specifically focusing on the role of religion and spirituality on cancer outcomes being too sparse to draw decisive conclusions. Further, research in this area presents numerous methodological issues. Due to these shortcomings, it is premature to determine the role of religion and spirituality in cancer, adjustment, and quality of life without the input of future research.
Regarding Religious Coping and BMT

Sherman, Plante, Simonton, Latif, and Anaissie (2009) assessed 94 multiple myeloma patients at two points during treatment: prior to stem cell collection, and after high-dose chemotherapy and stem cell transplantation. The authors sought to further understand the relationship between religious coping and health-related quality-of-life outcomes (i.e., physical, functional, social, emotional, and transplant-specific concerns) throughout the treatment process. Patients completed the Santa Clara Strength of Religiousness Faith (Plante & Boccaccini, 1997) to assess the strength of patients’ faith, and the Brief RCOPE (Brief Measure of Religious Coping; Pargament, Koenig, & Perez, 2000; Pargament, Smith, Koenig, & Perez, 1998) to assess patients’ style of religious coping in response to cancer. In addition, patients completed a measure of health-related quality-of-life, and a measure of psychosocial distress.

As expected, negative religious coping styles predicted modestly worse outcomes than positive religious coping styles. In addition, religious or spiritual struggling at the time of stem cell collection predicted more anxiety and depression, worse emotional well-being, and more transplant-related concerns post-transplant. Interestingly, patients who turned toward their faith for support, but felt they were being punished, alienated or felt uncertain (i.e., scored high on both positive and negative religious coping) experienced the most compromised physical well-being. Sherman et al. (2009) found little change in religious coping styles over time. However, patients who became more reliant on negative coping styles over time experienced a worsening of depression, emotional well-being, and physical and functional well-being compared to patients who remained stable in their use of negative religious coping. Nevertheless, more positive religious coping was not strongly related to better health outcomes.
Sherman et al. (2009) called for more longitudinal research to examine changes in religiosity over time. More research in this area is needed, especially for patients receiving BMTs, as few studies have examined the potential for negative religious or spiritual coping within a population undergoing aggressive and life-threatening treatment. Negative spiritual coping may be related to, or predictive of psychological distress. Therefore, it is important to recognize when distress may be caused by spiritual concerns so patients receive the care they need. It is also important to understand the times during the treatment process in which BMT patients are likely to be the most susceptible to religious or spiritual concerns and to be aware of the potential impact these concerns may have on the patient’s level of overall psychological distress. Longitudinal research including assessment at additional points in time would aid in further understanding how religious coping styles may change over the course of treatment.

Sherman et al. (2005) evaluated the religious coping styles of 213 multiple myeloma patients preparing for autologous stem cell transplantation. Despite this treatment, multiple myeloma patients have a poor long-term prognosis. In addition, the time prior to high-dose chemotherapy induction and transplantation appears to be one of the more stressful points of treatment when patients must contend with marked functional impairment, fatigue, and pain (Sherman, Simonton, Latif, & Tricot, 2004). Sherman et al. (2005) evaluated patients’ general religious orientation as assessed by the Santa Clara Strength of Religious Faith measure (Plante, & Boccaccini, 1997), and their cancer-specific religious coping (i.e., positive or negative) as assessed by the Brief RCOPE. Outcome measures for the study included self-report and clinician ratings of depression, psychological distress, daily physical functioning, fatigue, and pain.
The results indicated that only negative religious coping, not positive coping, was related to patient outcomes. Patients, who struggled with religiosity in response to cancer, experienced more general distress, depression, and to a lesser degree, fatigue, pain, and impaired physical functioning than patients who did not (Sherman et al., 2005). It is important to note that these findings were modest, but consistent and support similar results found in studies by Sherman and Simonton (2001), and Sherman, Simonton, Plante, Moody, and Wells (2001). Interestingly, these results mimic some research investigating positive and negative social interactions, including supportive and negative responses of partners, as well as other members of the social network. The absence of negative social interactions evoking disappointment, conflict, and tension between individuals may be better predictors of psychological adjustment than positive, supportive interactions (Manne, Taylor, Dougherty, & Kemeny, 1997; Schuster, Kessler, & Aseltine, 1990).

Importance of Social Support

The support of family, friends, and medical and psychosocial care providers is an important factor in BMT patient outcomes. Decker (1995) reported that family support is crucial to patients' quality of life before, during and after BMT. Importantly, Decker (1995) also noted that family members often become bone marrow donors, which "singles out" one family member as "key" to the treatment making family cohesiveness all the more necessary. The support of the medical staff is also vital during BMT to answer questions and diminish patients' feeling of loss of control (Decker, 1995). Syrjala et al. (2004) completed a five year longitudinal study in which 319 BMT patients were evaluated prior to transplantation, at ninety days, one year, three years, and five years post-transplantation. The authors discovered that patients with chronic GVH, less social support prior to transplantation, and women were more depressed after
transplant. Distress related to BMT was slower to recover for allogeneic transplant recipients and those with less social support prior to transplantation than other participants. The authors suggested that recovery may be accelerated by more effective interventions to improve social support and manage depression.

Some predictor variables related to social support have been identified in past research. For instance, partnership appears to play a significant role in patients' perception of social support. According to Frick, Rieg-Appleson, Tyroller, and Bumeder (2005), BMT patients living with a partner displayed higher scores on a measure of positive interaction than patients living alone. Frick et al. (2005) invited 155 patients to participate in their study and asked them to nominate a spouse/partner, friend, or child as their primary source of support. Over 70% of patients nominated their spouse/partner. Patients who received support from a spouse/partner reported better health-related quality of life (HRQL) than patients who nominated another person as their source of support. Although beyond the scope of the current study, the authors also concluded that the HRQL of caregivers was only slightly better than that of patients and the needs of caregivers are often overlooked.

Gender also appears to play a role in social support. Women seem to benefit from a broad social network, whereas men seem to benefit more from the support provided by a spouse (Frick et al., 2005). However, Heinonen et al. (2001) concluded that regardless of the availability of social support and marital status, male BMT patients who received allogeneic transplants reported less satisfaction with social support than female patients. Social support literature indicates the emergence of gender differences occurs when the quality of relationships, as opposed to quantity, is measured. Turner (1994) theorized this finding may be due to women being more capable of providing and receiving emotional support than men; however, the
ultimate explanation remains unclear. Furthermore, results from a study conducted by Fife, Kennedy, and Robinson (1994) indicated females benefited more from family support, while males benefited more from support provided by health care professionals. Although not entirely understood, it is important to recognize gender differences when recommending and providing support for BMT patients.

Importantly, research has supported the conclusion that social support is predictive of the emotional and physical outcomes of BMT. Baker, Zabora, Jodrey, Polland, and Marcellus (1995), Colon, Callies, Popkin, and McGlave (1991), Rodrigue, Pearman, and Moreb (1999), Goetzmann et al. (2007), Hochhausen et al. (2007), and Wells, Booth-Jones and Jacobsen (2009) concluded that social support accounts for part of the variance in emotional and physical recovery. Wells et al. (2009) examined the level of social support available to 212 BMT patients prior to, and six months after BMT to determine whether a relationship existed between patients’ level of social support and level of anxiety and depression. Similar to Fife et al. (2000), Wells et al. (2009) found that higher levels of social support provided by family, friends, and health care providers were associated with lower levels of distress during the BMT process.

Colon et al. (1991) assessed 100 patients undergoing allogeneic BMT for the treatment of acute Leukemia to determine the relationship between psychosocial factors and length of survival following transplant. Three variables independently affected length of survival: illness, presence of depressed mood, and perceived social support. Patients who received a BMT during their first remission, as well as patients with a high level of perceived social support, had significantly improved survival rates, whereas patients with depressed mood had poorer outcomes. Moreover, Jenks and Altmaier (2008) assessed whether patients’ perception of low social support prior to transplant would predict whether they experienced higher levels of
depression one year post-transplant. A significant number of transplant patients with perceived
low social support were likely to continue experiencing feelings of depression throughout the
first year post-transplant even beyond what the authors predicted from pre-transplant depression
levels.

Hochhausen et al. (2007) examined whether social support, optimism, and self-efficacy,
assessed in 87 allogeneic BMT patients prior to transplant, predicted physical and emotional
well-being at one year post-transplant. The authors concluded that all three variables
significantly predicted both physical and emotional well-being post-transplant. This was true
even after controlling for age, GVH and treatment type. The authors affirmed that attention to
psychosocial issues in patients prior to transplantation is crucial and suggested that BMT patients
should be encouraged to expand their social support networks by reaching out to family and
friends, and by utilizing resources in their communities.

It is evident that social support is important for patients before, during, and after
hospitalization for BMT. As described earlier, the findings of a longitudinal study conducted by
Ho et al. (2002) support the positive impact of expressive, open and direct family relationships
on decreasing patient distress levels. What is unclear is the variability of perceived support, if
any, occurs during hospitalization for BMT, and what affect this may have on patients’ reported
level of psychological distress. While not a primary objective of the current study, changes in
perceived level of social support will be assessed weekly to determine the effect this may have
on patients’ level of distress.
Meaning in Life during Cancer

Meaning in life is an important and multi-faceted construct for humans, referring to the value and purpose placed on one’s life that may also encompass life goals and spirituality (Jim, Purnell, Richardson, Golden-Kreutz, & Andersen, 2006). Theorists, such as Viktor Frankl (1963) have proposed that humans instinctively seek meaning and fulfillment in their lives. Particularly intriguing, are the ways in which people find meaning in the midst of stressful and negative events. Life changing events, such as a diagnosis of cancer, may prompt changes in one’s previously held beliefs of meaning in life (Jim et al., 2006; Park & Folkman, 1997). Park and Folkman (1997) further differentiated between global and situational meaning in life; although, global meaning often strongly influences the meaning given to a situation or event. Global meaning refers to, “people’s basic goals and fundamental assumptions, beliefs, and expectations about the world” (Park & Folkman, 1997, p. 116) and encompasses an individual’s beliefs regarding his/her purpose in life. Religion and spirituality are cited as examples of global meaning. On the other hand, situational meaning refers to an individual’s ability to establish congruence between his/her global beliefs and goals, and the circumstances of the current situation. The amount of dissonance between an individual’s assigned global meaning and his/her appraisal of the meaning of the situation at hand determines the amount of subjectively felt stress. An individual experiencing considerable discord may need to reevaluate and change the assigned global meaning and/or the meaning assigned to the situation to arrive at a feeling of harmony (Skaggs & Barron, 2005).
It is common for cancer patients to engage in reappraisal of meaning in life after diagnosis and treatment, and these experiences may be even more paramount for patients undergoing rigorous treatment regimens such as BMT. Xuereb and Dunlop (2003) conducted a qualitative study with 10 Leukemia or Lymphoma survivors who underwent a BMT. The authors learned of the struggles the patients faced through diagnosis, treatment and survival during which personal meaning and agency were imperative to these individuals. In addition, Vickberg et al. (2001) examined the global meaning (i.e., the belief that life has purpose and coherence) and psychological adjustment of 85 BMT survivors via telephone interviews. After controlling for physical functioning, stressor severity, and gender, global meaning was inversely related to psychological distress suggesting that patients’ belief that life has purpose may reduce subjective levels of psychological distress.

Jim et al. (2006) developed the Meaning in Life Scale, an empirically validated measure, to assess multiple conceptualizations of meaning in life in cancer patients, unlike past measures derived from qualitative interviews or invalid items generated by the researcher. Jim et al. constructed the scale after a review of themes in the literature, including one’s sense of purpose in life, the belief in the value of life, the coherent explanation of life events (i.e., explaining why events have occurred and the values of those events to patients), well-being, and spirituality. The researchers also selected items from previous scales assessing one or more of the themes.

Jim et al. (2006) validated the measure using two samples of cancer patients. In their initial study, the researchers calibrated the measure using a homogeneous sample of 167 breast cancer survivors. Factor analysis was performed on the 39 items administered to the participants and yielded a four factor structure. The first factor was labeled harmony and peace; the second, life perspective, purpose, and goals; the third, confusion and lessened meaning; the fourth,
benefits of spirituality (Jim et al., 2006). In a second study, the researchers assessed the validity of the internal structure of the measure using a sample of 384 male and female survivors with various cancer diagnoses and treatments. This sample completed the Meaning in Life Scale as a web-based survey (Jim et al., 2006). A confirmatory factor analysis of the remaining items tested the generalizability of the results from the first study. The results of the second study replicated the 21-item, four-factor structure found in the first.

Visser et al. (2010) in a review of the literature regarding the positive relationship between spirituality and well-being, cited the Meaning in Life Scale (Jim et al., 2006) as one of the most commonly utilized measures to assess meaning in life. They held that authors who utilized the scale likely discovered a negative relationship between meaning in life and psychological distress because the scale contains several items that refer to positive affect, which is related to well-being. Visser et al. (2010) caution researchers to recognize the overlap of constructs within measures like the Meaning in Life Scale and encourage future research in the areas of spirituality and meaning in life to better understand the effect of both for cancer patients.

Interestingly, after the validation of their Meaning in Life Scale (MiLS), Jim and Andersen (2007) later discovered that meaning in life appears to mediate the relationship between social and physical functioning and distress among cancer survivors. Physical and social impairments in functioning were defined as increased symptoms, fatigue, pain, and decreased social activity, ability to meet social obligations, and disruption of ties with family members and friends. The authors hypothesized that because compromised social and physical functioning can lead to increased psychological distress for patients, they may begin to question previously held beliefs about meaning in life during this time. As such, the authors expected meaning in life, as assessed by the MiLS, to mediate the relationship between functioning and
distress, as assessed by the Medical Outcomes Study-Short Form (Ware, Kosinski, & Keller, 1994), and the Profile of Mood States-Short Form (DiLorenzo, Bovbjerg, Montgomery, Valdimarsdottir, & Jacobsen, 1999).

Jim and Anderson (2007) utilized two samples of participants, a heterogeneous sample of cancer survivors and breast cancer survivors, respectively. Within the second sample, the effect of social functioning impairment on distress was fully mediated by meaning in life; whereas, the effect of physical impairment on distress was partially mediated by meaning, leaving the possibility of other mediating factors. Within the first sample, meaning in life was a significant partial mediator between social and physical impairment and psychological distress. The current study explores meaning in life during treatment by examining the possibility of change in meaning during BMT.

Summary

Over the past 40 years, bone marrow transplantation (BMT) has been employed with increasing frequency and success to treat numerous diseases (Moore, 2008). The process of BMT can engender a great deal of emotional and physical distress in patients and their families (Lesko, 1994; Stewart & Sugar, 2002). Leading institutions such as the National Comprehensive Cancer Network (NCCN) recognize psychological distress as a significant concern for individuals with cancer and strongly recommend routine assessment of distress (Holland et al., 2010). As suggested, the initial step in managing distress is administering a self-report measure, such as the Distress Thermometer (Roth et al., 1998) as it assesses the primary causes of distress including physical, emotional, social, practical, and spiritual concerns.
High levels of distress are common among cancer patients (Hoffman et al., 2004; Jacobsen et al., 2005; Trask et al., 2002). One third to over one half of cancer patients report significant distress (Carlson et al., 2004; Lee et al., 2005; Zabora et al., 2001), whereas fewer than 10% of these patients are referred for professional psychosocial care (Carlson & Bultz, 2003). Unfortunately, distress is often not recognized by oncology professionals, and thus patients are not referred for psychosocial intervention (Fallowfield et al., 2001; Sollner et al., 2001).

Research regarding the trajectory of distress among cancer patients at various stages in the illness is crucial as increased levels of distress have been associated with poorer treatment adherence, decreased satisfaction with care, and poorer quality of life (Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000). A few longitudinal studies have investigated the effect of psychosocial variables prior to and during BMT. Fife et al. (2000) found the time of greatest distress occurred after hospital admission and before bone marrow infusion, during which there was a significant increase in anxiety, depression, and uncertainty. Patients experienced a gradual decline in uncertainty and anger throughout hospitalization, and both anxiety and uncertainty dropped significantly after discharge from the hospital (Fife et al., 2000). In contrast, Molassiotis et al. (1996) found high psychological morbidity was present the day before transplant, but remained elevated throughout hospitalization and a month after hospital discharge. Interestingly, Fife et al. (2000) also concluded that the variable most strongly and consistently related to emotional response was personal control. Likewise, Baker et al. (1997) found that personal control, as measured by the Mastery Scale (Pearlin et al., 1981; Pearlin & Schooler, 1978), and dispositional optimism, were predictive of psychosocial adjustment.
Religion and spirituality can be valuable resources for individuals with cancer (Halstead & Fernsler, 1994; Sherman et al., 2000), with some research indicating positive correlations between religiosity and enhanced coping, or more effective adjustment to illness (Sherman & Simonton, 2001). Sherman et al. (2009) sought to further understand the relationship between religious coping and health-related quality-of-life outcomes throughout the BMT treatment process. As expected, negative religious coping styles predicted modestly worse outcomes than positive religious coping styles. In addition, religious or spiritual struggling at the time of stem cell collection predicted more anxiety and depression, worse emotional well-being, and more transplant-related concerns post-transplant. In a related study, Sherman et al. (2005) reported that only negative religious coping, not positive coping, was related to patient outcomes and patients who struggled with religiosity in response to cancer experienced more general distress than patients who did not.

The support of family, friends, and medical and psychosocial care providers is another important factor in BMT patient outcomes. Research supports the conclusion that social support is predictive of the emotional and physical outcomes of BMT. Colon et al. (1991), Baker et al. (1995), Rodrigue et al. (1999), Goetzmann et al. (2007), Hochhausen et al. (2007), and Wells, Booth-Jones, and Jacobsen (2009) concluded that social support accounts for part of the variance in emotional and physical recovery. It is evident that social support is important for patients before, during, and after hospitalization for BMT.

It is common for cancer patients to engage in reappraisal of meaning in life after diagnosis and treatment, and these experiences may be even more paramount for patients undergoing rigorous treatment regimens such as BMT (Xuereb & Dunlop, 2003). Vickberg et al.'s (2001) results suggested patients' belief that life has purpose may reduce subjective levels
of psychological distress. After validating their Meaning in Life Scale (MiLS), Jim and Andersen (2007) later discovered that meaning in life appears to mediate the relationship between social and physical functioning and distress among cancer survivors.

As suggested by Fife et al. (2000), additional prospective longitudinal research is needed if effective intervention strategies addressing psychological, emotional, and social complications are to be implemented for patients undergoing BMT. Additionally, Sherman et al. (2009) called for future researchers to examine changes in religiosity over time. Further research in this area is needed to determine whether negative religious or spiritual coping may be related to, or predictive of psychological distress.
Chapter II

Rationale and Hypotheses

Past research suggests that cancer patients undergoing active treatment, such as bone marrow transplant (BMT), may be among those who experience the most distress (Carlson et al., 2004). The extended hospital stay during transplantation likely adds to distress levels, but also presents a crucial opportunity for psychosocial treatment team members to address patient distress. Current measures of distress, including the Profile of Mood States (POMS), Psychosocial Adjustment to Illness Scale (PAIS), Brief Symptom Inventory (BSI), Symptom Checklist 90-R (SCL-90), State-Trait Anxiety Inventory, Center for Epidemiological Studies Depression Scale (CESD), and Beck Depression Inventory (BDI) are relatively lengthy and were not designed to specifically address the concerns of patients enduring bone marrow transplants.

The Distress Thermometer (DT) and Patient Problem List (National Comprehensive Cancer Network, 2003; Ransom, Jacobsen, & Booth-Jones, 2006; Roth et al., 1998) were specifically developed to assess levels of distress and identify its causes in cancer patients. The DT is a simple one-item measure. The Problem List accompanies the DT, aiding clinicians in better understanding the causes of patients’ distress, including physical, emotional, social, practical, and spiritual concerns.
Prior to construction of the Jewish Hospital BMTU Distress Screening Measure, Jewish Hospital psychology staff used the DT and the Patient Problem List (NCCN, 2003) to assess distress during psychology rounds for eight consecutive weeks. However, several problems were encountered. The Distress Thermometer focuses on distress over the past week; it does not separately inquire about current levels of distress. In addition, the Patient Problem List focuses heavily on physical problems, neglecting issues of spirituality and religion almost completely, addressing these concerns with only one item. There are also relatively few inquiries into emotional concerns, leaving patients without the option of indicating boredom, loneliness and homesickness which are commonly endorsed by BMT patients at Jewish Hospital. Likewise, asking patients about sexual interest/activity and loss of interest in regular activities is irrelevant for this population during their hospitalization. Furthermore, the wording of some inquiries in the Patient Problem List seemed vague and meaningless; for instance, inquiries about family problems referenced “dealing with children and significant other” were considered objectionable by patients and reworded to inquire about “worries about children, partner/spouse/caregiver,” and “conflict in family”.

In response to concerns of BMT inpatients and clinicians that the DT and Patient Problem List (NCCN, 2003) did not adequately assess issues among this specific patient population, Lyn Sontag, Psy.D., ABPP constructed The Jewish Hospital BMTU Distress Screening Measure at The Jewish Hospital in Cincinnati, Ohio. Dr. Sontag, with the assistance of clinical psychology trainees from Xavier University, successfully utilized the measure during weekly psychology rounds to assess the levels of distress of patients on the BMT unit and determine the etiology of distress. The Jewish Hospital BMTU Distress Screening Measure retains the face validity of the DT and Patient Problem List, and utilizes similar domains of concern, including practical,
family, emotional, physical, and spiritual issues as the previously validated Patient Problem List. However, the Jewish Hospital BMTU Distress Screening Measure has been reorganized and expanded to better fit the needs of BMT inpatients and aid the staff in assisting patients.

The current study aims to seize the crucial opportunity presented during hospitalization to assess and assist BMT patients with psychological distress, as well as add a validated measure of distress specifically designed for use with BMT inpatients to the existing literature. The Jewish Hospital Distress Screening Measure is designed to assess the numerous causes of distress within BMT inpatients including emotional, spiritual, practical, familial and physical concerns. It is evident that additional measures may be useful in identifying areas that may also increase a patient’s level of distress. For this reason, personal control, sense of meaning in life, and religious coping styles will also be assessed. Unique to this study, the MiLS will be utilized to examine change in patient perspective of meaning during the BMT process, as well as a potential interaction with religious coping and change over time. The trajectory of distress established in this study will also serve to increase the generalizability of the results of preceding studies (e.g., Fife et al., 2000; Ho et al., 2000; Molassiotis et al., 1996), while assessing a unique combination of variables to determine the amount of variance accounted for in the overall distress levels of patients. Additionally, BMT patient distress levels will be assessed more frequently than in past studies (e.g., Ho et al., 2002; Sherman et al., 2009; Wells et al., 2009) to gain a more detailed depiction of a trajectory of distress during transplantation. Finally, the data from this study will offer valuable information to the Bone and Marrow Transplant Program at Jewish Hospital and aid in patient care.
Hypotheses

Primary hypotheses for this study include:

1. Patient distress levels are highest the day prior to BMT, as measured by the Distress Thermometer and Jewish Hospital BMTU Distress Screening Measure, and decrease throughout the rest of the hospitalization.

2. Emotional concerns, as measured by the emotional issues section of the Jewish Hospital Distress Screening Measure, are positively predictive of the patient’s overall distress, as measured by the Jewish Hospital Distress Screening Measure.

3. Spiritual concerns, as measured by the spiritual concerns section of the Jewish Hospital Distress Screening Measure, are positively predictive of the patient’s overall distress, as measured by the Jewish Hospital Distress Screening Measure.

4. Practical concerns, as measured by the practical issues section of the Jewish Hospital Distress Screening Measure, are positively predictive of the patient’s overall distress, as measured by the Jewish Hospital Distress Screening Measure.

5. Family concerns, as measured by the family issues section of the Jewish Hospital Distress Screening Measure, are positively predictive of patient overall distress, as measured by the Jewish Hospital Distress Screening Measure.

6. Physical concerns, as measured by the physical issues section of the Jewish Hospital Distress Screening Measure, are positively predictive of patient overall distress, as measured by the Jewish Hospital Distress Screening Measure.

7. Personal control, as assessed by the Mastery Scale, are negatively predictive of patient overall distress, as assessed by the Jewish Hospital Distress Screening Measure.
8. Sense of meaning in life and positive religious coping style are negatively predictive of patient overall distress before, during, and after BMT, as assessed by the Jewish Hospital Distress Screening Measure.

A secondary aim for this study is to validate the Jewish Hospital Distress Screening Measure for use with BMT inpatients. The DT and HADS will be used to establish convergent validity with the Jewish Hospital Distress Screening Measure. Additional exploratory analyses will be conducted based on demographic data collected from patients prior to hospitalization. The results of past studies have indicated women, people of minority status, younger patients, and those with lower incomes may be more susceptible to high levels of distress (Carlson et al., 2004; Jacobsen et al., 2005). The ability of perceived social support to predict patient distress has been recognized by past researchers (Baker et al., 1995; Colon et al., 1991; Decker, 1995; Goetzmann et al., 2007; Hochhausen et al., 2007; Rodrigue et al., 1999; Syrjala et al., 2004; Wells et al., 2009). Although it is not one of the principal intentions of the current study, perceived social support is clearly an aspect that can influence patient distress and will be assessed through the use of a single, face-valid question constructed by the researcher.
Chapter III
Method

Participants

Approximately 100 bone marrow transplant inpatients of Jewish Hospital were invited to participate in the current study. The number of participants necessary to test the hypotheses with adequate power was computed using G*Power analysis (Buchner, Erdfelder, & Faul, 1997). To test the correlational hypotheses, Cohen (1992) suggests at least 85 individuals with a power of .80 and an alpha of .05 (assuming a medium effect size). This sample size (85) over three to five time periods would also, based on the G*Power analysis, be sufficient to detect a medium effect size using a repeated-measures ANOVA. In sum, 100 participants were determined to be more than sufficient to test both the correlational and repeated-measures portions of the design.

To be eligible for participation, patients were required to be of 18 years of age or older and fluent in English. Participants could be male or female, and of any race, ethnicity, socioeconomic status, or religion. Participants included only individuals receiving their first autologous or allogeneic BMT. Patients who had previously received a BMT were not invited to participate. All participants provided their voluntary, informed consent to participate in the study before completion of any of the measures. Participants were not provided with monetary compensation for time invested in the study; however, completion of the measures aided clinicians in providing them with more comprehensive mental health care, as well as assist in providing future BMT patients with the best care possible.
Measures

Distress Thermometer

The Distress Thermometer (DT) is a single-item, self-report measure of psychological distress (NCCN, 2003; Ransom et al., 2006; Roth et al., 1998; see Appendix A). The response format is a Likert scale in the shape of a vertical thermometer ranging from zero, which indicates no distress, to 10, which indicates extreme distress. Patients are instructed to indicate their level of distress over the past week, including today. Accompanying the DT is the Patient Problem List consisting of five categories in which patients indicate causes of their distress with a check mark. The distress categories consist of practical, family, emotional, and physical problems, and spiritual/religious concerns. Practical problems include, “child care, housing, insurance/financial, transportation, and work/school.” Family problems include, “dealing with children, dealing with partner, and ability to have children.” Emotional problems include, “depression, fears, nervousness, sadness, worry, and loss of interest in usual activities.” Physical problems include, “appearance, bathing/dressing, breathing, changes in urination, constipation, diarrhea, eating, fatigue, feeling swollen, fevers, getting around, indigestion, memory/concentration, mouth sores, nausea, nose dry/congested, pain, sexual, skin dry/itchy, sleep, and tingling in hands/feet.” The spiritual/religious concerns category is a single item inquiry that does not require patients to indicate further information other than whether spirituality/religion is a concern for them at this time.

The NCCN published the DT and Patient Problem List in 2003 to assess levels of distress and identify its causes in cancer patients. Roth et al. (1998) originally pilot tested the DT for use with prostate cancer patients. Roth et al. (1998) found the DT to be an acceptable brief measure of distress and referred patients with scores of five and above for further psychiatric evaluation.
In conjunction with the DT, patients also completed the HADS. The rate of agreement between the two scales, in terms of identifying distress was 74.4% when using a cutoff score of five on the DT and 15 on the HADS. Ransom et al. (2006) later validated the DT and Patient Problem List for use with BMT patients. Ransom et al. (2006) established criterion validity for the DT using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977) and the State-Trait Anxiety Inventory-State Version (STAI-S; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). When using a CES-D cut-off score of 16, study participants averaged distress scores of 10.9 on the CES-D, 39.4 on the STAI-S, and 3.4 on the DT. The authors determined a DT score of four to be indicative of a clinically significant level of distress. Ransom et al. (2006) reported the DT significantly correlated with the CES-D ($r=0.59$, $p<0.0001$) and the STAI-S ($r=0.58$, $p<0.0001$) indicating that the DT shares a substantial amount of variance with the CES-D and the STAI-S.

Jacobsen et al. (2005) found similar results indicating the DT is comparable to longer measures screening for distress. They compared the DT to the HADS and the BSI-18. Using Receiver Operating Characteristic (ROC) curve analyses, they also determined a cut-off score of four on the DT allowed for optimal sensitivity and specificity relative to the other measures. Mitchell (2007) reported “ultra-short methods” of screening for distress in cancer patients, including the DT, are modestly effective in screening for mood disorders. Mitchell (2007) cautioned that ultra-short methods should not be used alone to diagnose depression, anxiety, or distress in patients, but they can be used effectively to initially rule-out depression. The author examined 38 diagnostic validity studies of ultra-short screening measures, 19 of which assessed the DT. Mitchell (2007) determined a sensitivity of 78.4% for the pooled ability of ultra-short measures to detect depression, with a specificity of 66.8%, a positive predictive value of 34.2%,
and a negative predictive value of 93.4%. These results demonstrate the tools’ collective ability to exclude possible cases of depression, although they performed poorly in confirming a suspected diagnosis. The measures’ pooled ability to detect anxiety demonstrated a sensitivity of 77.3% and specificity of 56.6%; for distress, the authors reported a sensitivity of 78.3% and a specificity of 66.5%. The DT performed very similarly to the pooled results, with the exception that the DT was slightly less capable of avoiding false positives. The DT generated nine false positives in every 20 cases in comparison to the seven out of 20 false positives detected by the other measures. It is likely that out of every 100 people screened with the DT, 40 probable cases of distress would be identified, of which 18 would be false positives, and 60 probable non-cases, of which nine would actually be distressed and missed. The author suggested that the data indicate the ultra-short measures, such as the DT, are best at ruling out cases of depression, anxiety, or distress with an accuracy rating of 85-90%, but can be used with only a 34-60% accuracy rating to rule in depression, anxiety, or distress. Of course, the accuracy of the measures can change when the cut-off thresholds are altered.

Mitchell (2010) determined the DT and the HADS perform with approximately the same accuracy, stating it makes sense to choose a measure based on acceptability or cost-effectiveness. The accuracy of the single-item DT seemed comparable to that of the 14-item HADS, whereas its efficiency was far superior. While Mitchell (2010) warned that no screening tool should be used as an alternative to careful clinical assessment, ultra-short methods of screening are substantially more efficient and may be more acceptable to patients, making them a useful initial tool for clinicians. Additionally, Mitchell (2010) concluded that the DT and HADS perform with approximately the same accuracy as the Psychological Distress Inventory (PDI; Lustman, Sowa, & Ohara, 1984), a single verbal question, the combined DT, an impact thermometer, and
combined two verbal questions. In another study conducted by Trask et al. (2002), the DT correlated well the HADS when BMT patients were assessed for psychological distress with both the DT and the HADS. There was significant correlation between ratings using the DT and HADS; on average, patients responded with low to moderate levels of distress on the DT and low to moderate levels of anxiety and low levels of depression on the HADS.

**The Hospital Anxiety and Depression Scale (HADS)**

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; see Appendix B) is a self-report scale originally constructed for use with medical patients to aid in identifying patients who have experienced symptoms of depression and anxiety over the past week. Participants completing the scale respond to questions regarding their level of tension, interest, fearfulness, ability to laugh, worries, cheerfulness, ability to relax, energy, nervousness, appearance, restlessness, hope, panic, and enjoyment. The HADS consists of 14 items, with a Likert-type response format ranging from zero to three. A score of zero indicates a disconfirming response (i.e., not at all, hardly at all, or only occasionally). Likewise, a score of three indicates an affirmative response (i.e., most of the time, very definitely, and nearly all the time). Items 2, 4, 6, 7, 12, and 14 are reversed scored. Patients’ responses are then totaled resulting in a final score ranging from zero to 21. Those with final scores of zero through seven are considered within the “normal range”; those with scores from eight to 10 are considered “borderline abnormal”; those with scores from 11-21 are considered “abnormal” (Zigmond & Snaith, 1983). The scale generally takes two to five minutes to complete (Snaith, 2003). Zigmond and Snaith (1983) chose to eliminate physical symptoms of distress from the measure which could lead to false positive results in medical patients.
The HADS is widely accepted by patients, clinicians, and researchers, with the vast majority of patients willing to complete the measure (Herrmann, 1997). Internal consistency of the English version of the HADS has been deemed acceptable at 0.80 to 0.93 for the anxiety subscales and 0.81 to 0.90 for the depression subscales. Test-retest reliability for zero to two weeks has been established at 0.84 for anxiety and 0.85 for the depression subscale, dropping to 0.73 and 0.76 respectively between two and six weeks, and 0.70 and 0.70 respectively after six weeks and beyond (Herrmann, 1997).

Factor analysis resulted in one anxiety and one depression factor, which have remained stable across subgroups accounting for approximately 50% of the variance. In 18 separate studies with a total of 8,160 participants, the correlation between the anxiety and depression subscales was $r=0.63$, indicating they are correlated in most patient groups. Although, there is evidence that the subscales differ in clinically meaningful ways, several studies have demonstrated that the HADS anxiety subscale (HADS-A) has correlated significantly higher with other measures of anxiety than the depression subscale (HADS-D). Likewise, the HADS-D has correlated significantly higher with other measures of depression than the HADS-A (Herrmann, 1997). As reported by Herrmann (1997), there is no single, generally accepted cut-off score for the HADS. Zigmond and Snaith (1983) recommended a cut-off score of seven or eight for possible anxiety or depression, and 10 or 11 for probable anxiety or depression; other researchers have utilized different cut-off scores. The HADS manual (Snaith & Zigmond, 1994) also suggested a cut-off score of 14 or 15 indicating severe anxiety or depression.
Although the HADS manual does not recommend that a total score be generated, it has been widely used as an indicator of overall distress. Singer et al. (2009) determined it is important to decide whether high detection rates of affected patients or low misclassification rates are more important when choosing an appropriate cut-off score. With a cut-off score of 13 or above it was possible to detect 76% of those with a mental disorder; whereas, 95% of the cases could be identified with a cut-off score of six or above. Likewise, a cut-off score of 16 or above was able to identify 59% of cases and a cut-off score of 22 or above was able to identify 30% of cases of those with a mental disorder. Again, the HADS should not be used alone to diagnose anxiety or depression; clinical expertise is necessary.

In a review of the literature including 747 articles about the HADS, Bjelland, Dahl, Haug, and Neckelmann (2002) concluded the HADS performed well in assessing symptom severity and identifying cases of anxiety disorders and depression in somatic, psychiatric and primary care patients, and in the general population. They also identified the number of factors within the HADS by analyzing past research which utilized factor analyses, the correlations between the subscales, and the internal consistency of the subscales (i.e., Cronbach’s alpha). They reported most studies demonstrated two factors which were consistent with the HADS depression and anxiety subscales; correlations between these two subscales varied from .40 to .74. Cronbach’s alpha for the HADS-D varied from .67 to .90 and for the HADS-A from .68 to .93. Bjelland et al. (2002) found correlations between the HADS and other measures of depression and anxiety, such as the General Health Questionnaire (HGQ), the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory (STAI), the Clinical Anxiety Scale (CAS), and the Symptom Checklist-90 (SCL-90), ranged from 0.49 to 0.83. The authors also established an optimal
balance between sensitivity and specificity for the HADS, which was defined as a score of eight or above on both the HADS-A and HADS-D.

More recently, Vordermaier, Linden, and Siu (2009) reviewed literature relevant to the validation of the HADS in oncology settings, concluding the HADS demonstrated adequate internal consistency and was sensitive to change in cancer patients. The authors also assessed the discriminant validity of the HADS by comparing it to other clinical assessments. Ten studies concluded the HADS performed well in comparison to the other measures, 14 concluded the HADS performed moderately well, and two concluded it did not perform well. Some studies reported the anxiety subscale performed better than the depression subscale, whereas others suggested the psychometric properties of the HADS total score were at least comparable, perhaps superior, to those of the anxiety or depression subscales. The authors indicated they were, however,

Disconcerted to find that cutoffs for distinguishing anxious or depression patients from nonanxious or nondepressed patients differed widely across studies and that this variability had not been justified. The cutoffs for the HADS total score ranged from 8 to 22 and for the subscale scores from five to 11. (p. 1481)

In 2010, Luckett et al. reviewed measures of anxiety, depression and general distress in studies that evaluated measures for psychosocial interventions with English-speaking adults with heterogeneous diagnoses of cancer. Luckett et al. (2010) evaluated 30 self-report outcome measures on the basis of seven criteria including: (1) suitability for people undergoing active cancer treatment of any type or stage; (2) reliability and validity in English-speaking cancer patients; (3) track record in identifying treatment effects in randomized clinical trials of psychosocial interventions; (4) clinical meaningfulness of scores; (5) availability of comparison data from cancer and general populations; (6) efficacy based on number of items and number of constructs assessed; (7) ease of administration and cognitive burden. The HADS scored highest
of all measures with a weighted score of 77.5 of a possible 100 points. The HADS scored highest overall, in part, due to extensive evidence supporting its psychometric properties and its efficiency in providing scores of anxiety, depression and distress with only 14 items. The HADS omits somatic symptoms of depression and anxiety to avoid confounding psychological symptoms with symptoms disease or treatment. Whereas, the HADS performed well in samples of individuals with poor health status, those enduring active treatment, and in the general population, it performed surprisingly poorly in advanced cancer patients. The authors hypothesized this may be due to the HADS’ emphasis on anhedonia as opposed to somatic symptoms. However, anhedonia may occur in this population for reasons other than depression. Several of the studies reviewed by Luckett et al. (2010) reported the HADS is superior in screening for anxiety than depression; although, the authors recommended the continued use of the HADS-D in combination with the HADS-A and the combined HADS score when mixed affective disorders are of interest.

**Mastery Scale**

The Mastery Scale is a seven item, self-report measure utilized by Pearlin et al. (1981) to assess the extent to which participants perceive themselves as in control of their lives (see Appendix C). The Mastery Scale (Pearlin et al., 1981) utilizes a four-point Likert-type response format, (i.e., strongly agree, agree, disagree, or strongly disagree) with agreement indicating lack of personal control and disagreement indicating personal control. The scale is face valid, consisting of items such as, “I have little control over the things that happen to me”, “I often feel helpless in dealing with the problems in my life”, and “I can do just about anything I really set my mind to do.” Items six and seven are reversed scored. Participants are given little instruction
and are simply asked, "Please circle the response that indicates how strongly you agree or disagree with each statement."

Pearlin and Schooler (1978) first developed the Mastery Scale as part of a larger study to assess psychological coping resources. Pearlin and Schooler (1978) utilized varimax rotation to determine seven items loaded onto the mastery factors. They examined data collected from 2,300 participants from 1972 through 1973. Pearlin et al. (1981) later utilized longitudinal data, including Pearlin and Schooler's (1978) original data as a first wave, and 1,106 of the original participants assessed from 1976 through 1977 as a second wave. Pearlin et al. (1981) subjected the seven items of the Mastery Scale to factor analysis. Test-retest reliability was demonstrated by a statistically significant correlation ($r = .44$) between time one and time two assessments. The authors utilized LISREL procedures, which allowed them to estimate the degree to which the scale was affected by correlated errors and the invariance of factor structure at the two time points. They concluded the relationship between the constructs and indicators remained stable over time, and that error was small and did not significantly influence the stability of their estimates.

Convergent validity of the Mastery Scale was supported by pairwise correlations with measures believed to measure similar constructs to mastery; in the same way, discriminate validity was supported by the near zero correlations with measures hypothesized to measure constructs other than mastery (Pearlin et al., 1978; Robinson, Shaver, Wrightsman, 1991). For instance, the Mastery Scale negatively correlated with a measure of depression (e.g., $r = -.20$ at time one and $r = -.43$ at time two). Alternatively, the Mastery Sale positively correlated with a measure of self-esteem (e.g., $r = .26$ at time one and $r = .54$ at time two). Likewise, Fife et al. (2000) compared measures of emotional response (i.e., anxiety, depression, anger, uncertainty)
with personal control (as measured by the Mastery Scale). During hospitalization, emotional response decreased as personal control increased.

**Brief RCOPE**

The Brief RCOPE (Pargament et al., 2000) is a 14 item, self-report measure of religious coping, consisting of two subscales that assess positive and negative religious coping styles (see Appendix D). Response options range from one to four (i.e., not at all, somewhat, quite a bit, and a great deal) regarding the frequency with which participants utilize a method of coping with a negative event (in the current study referring to BMT). The first seven items refer to positive religious coping styles including such items as: “Looked for a stronger connection with God,” and “Sought God’s love and care.” The last seven items of the scale refer to negative religious coping styles including such items as: “Wondered whether God had abandoned me,” and “Felt punished by God for my lack of devotion.”

The Brief RCOPE was derived from the original RCOPE consisting of 21 subscales each consisting of five items measuring religious coping. The RCOPE was factor analyzed and two factors emerged, measuring positive and negative patterns of coping. A subset of seven items was selected from each of the factors. Items with the largest factor loadings, items that loaded clearly on only one factor, and items from a variety of subscales were chosen to represent the items of the RCOPE (Pargament et al., 2000). Seven positive and seven negative religious coping items comprise the finalized Brief RCOPE.

Both the positive and negative coping subscales have demonstrated internal consistency and discriminant validity (Pargament et al., 2000). Pargament et al. (2000) suggest the Brief RCOPE is likely a better predictor of health-related outcomes than generic measures of religiousness used in past research (i.e., frequency of prayer, church/synagogue attendance, etc.).
However, Pargament et al. (2000) warns that the Brief RCOPE does not fully encompass all relevant information regarding religious coping and is not intended as a substitute for a more thorough analysis of specific religious coping methods. Pargament et al. (1998) reported moderate to high internal consistency for each scale. Two populations were assessed including college students and hospital patients over the age of 55. Cronbach's alpha coefficient estimates were .90 and .87 and .81 and .69 for the positive and negative scales, respectively, within the two populations. The positive and negative religious coping scales were significantly positively correlated with each other in both the college and hospital samples, $r = 17, p<.001$ and $r = .18, p<.001$, respectively. Although significant, this correlation is relatively low, which Pargament et al. (1998) suggest is evidence that the two scales are distinctive.

**Meaning in Life Scale**

The Meaning in Life Scale (MiLS) was developed by Jim et al. (2006) to assess the meaning individuals assign to events in their lives (see Appendix E). The MiLS is a self report instrument that includes 21 items referring to the possible impact of cancer on participants’ lives. Participants are asked to indicate how much they agree or disagree with statements about their lives at the present time. The response format is a six-point Likert scale with responses ranging from strongly disagree to strongly agree. To determine a total meaning score, scores for each of the four subscales are first totaled. The four subscales are: Harmony and Peace (consisting of items 15, 16, 17, and 18), Life Perspective, Purpose, and goals (consisting of items 2, 3, 8, 10, 11, 12, and 13), Confusion and Lessened Meaning (consisting of items 1, 4, 5, 6, 7, 9, and 14), and Benefits of Spirituality (consisting of items 19, 20, and 21). Item 16 is reversed scored. Higher subscale scores denote greater positive meaning, except for the Confusion and Lessened Meaning scale, for which higher scores denote greater confusion and less meaning. For this
reason, a total meaning score is computed by summing the three “positive” meaning scales and then subtracting the score for the Confusion and Lessened Meaning scale. The total meaning score can range from negative three to 17, with higher scores indicating greater positive meaning. (Jim et al., 2006). Example inquiries include, “As a result of my cancer diagnosis and treatment, I do NOT value life as much as I used to,” and “As a result of my cancer diagnosis and treatment, I have found new and more worthwhile goals.”

Jim et al. (2006) reported internal consistency of the MiLS as 0.93 for the total score with considerable homogeneity among the items. Two week test-retest reliability was 0.80 for the total measure. The total MiLS score was moderately positively correlated with the Medical Outcomes Study-Short Form used to assess physical and psychological quality of life ($r=0.58$), and negatively correlated with the CES-D assessing symptoms of depression ($r=-0.58$) and the POMS assessing psychological distress ($r=-0.62$).

**The Jewish Hospital BMTU Distress Screening Measure**

The Jewish Hospital BMTU Distress Screening Measure was constructed by psychologist, Lyn Sontag, Psy.D., ABPP at The Jewish Hospital in Cincinnati, Ohio (see Appendix F). The measure has been successfully utilized to aid health care providers in recognizing the distress of patients and has also been useful in providing referrals to the social worker, psychologist, and chaplain. The Jewish Hospital BMTU Distress Screening Measure is a self-report measure of psychological distress. Participants indicate their current (i.e., today’s) level of distress on an 11-point Likert scale with responses ranging from zero, indicating no distress, to 10, indicating extreme distress. Utilizing the same response format, participants then indicate their level of distress over the past week. Participants then report the extent to which five specific areas of concern have impacted their level of distress over the past week, including
today, utilizing an 11-point Likert response ranging from no problem to extreme problem. These areas of concern include practical issues, family issues, emotional issues, spiritual concerns, and physical issues. Practical issues include inquiries about housing, financial, and work concerns, as well as concerns for the daily care of children. Family issues include inquiries about worries about children, spouse, and conflict within the family. Emotional issues include feelings of sadness, anxiety, fear, boredom, loneliness, and homesickness. Spiritual concerns include feeling a sense of meaning and purpose, feeling cared for by a higher power, and feeling support from one's spiritual community. Physical issues include distress caused by the side effects of treatment, problems eating, pain, and fatigue.

Prior to the construction of the Jewish Hospital BMTU Distress Screening Measure, the Distress Thermometer and the Patient Problem List were used during psychology rounds for eight weeks to assess patients' level of distress. Several issues were encountered during the utilization of the Distress Thermometer and Problem List. The Distress Thermometer focuses only on distress over the past week and does not inquire about current levels of distress. In addition, the Patient Problem List focuses heavily on physical problems and neglects issues of spirituality and religion almost completely, addressing these concerns with only one item. There are also relatively few inquiries into emotional concerns leaving patients without the option of indicating boredom, loneliness and homesickness which are commonly endorsed by bone marrow transplant patients at Jewish Hospital. Likewise, asking these patients about sexual interest/activity and loss of interest in activities is irrelevant for this population during their hospitalization. The wording of some inquiries in the Patient Problem List seemed vague and meaningless; for instance, inquiries about family problems referenced “dealing with children and
significant other” were considered objectionable and reworded to inquire about “worries about children, partner/spouse/caregiver,” and “conflict in family”.

The Jewish Hospital BMTU Distress Screening Measure retains face validity and utilizes similar domains of practical, family, emotional, physical, and spiritual issues as the previously validated Patient Problem List, but has been reorganized and expanded to better fit the needs of bone marrow transplant inpatients and aid the staff in better assisting patients. In addition, a Likert scale was introduced to more thoroughly assess patients’ level of distress and gain an accurate depiction of the level of concern expressed for each issue. This also aids in the treatment and referral of patients. The measure can be used to talk with patients about endorsed items and plan interventions if necessary and is placed in medical charts to notify other interdisciplinary care team members about current interventions and progress.

Procedure

The analyses for the current study will be based upon archival data collected on the bone marrow transplant unit (BMTU) of Jewish Hospital beginning in October of 2010 and lasting approximately 10 months. The following is an explanation of the data collection process. All bone marrow transplant patients of Jewish Hospital receiving autologous or allogeneic transplants during the time of data collection, who met the criteria for participation, received information regarding the study during their pre-transplant psychological evaluations. Patients who had undergone a previous BMT were not eligible for participation in the current study as their expectations regarding the treatment process may have influenced their level of distress. Pre-transplant evaluations occurred approximately two to six weeks prior to hospital admission for BMT. The psychologist at the Jewish Hospital, or a clinical psychology doctoral student, verbally introduced the study to potential participants during their evaluation. The introduction
of the study was somewhat informal; however, patients received detailed information about the study. The informed consent form (see Appendix G) outlined what would be asked of participants should they agree to participate and the amount of time required to complete the measures. Participants were given a copy of the signed informed consent form upon request. Additionally, the psychologist or psychology student presented potential participants with all of the measures for review during their pre-transplant evaluation so they would fully understand what their participation would involve. Once participants expressed interest in participating, they were asked to provide their written informed consent. Participants were informed of their right to decline participation in the study, as well as their right to withdraw at any time without penalty. The investigators of this study obtained approval from Jewish Hospital’s Institutional Review Board to conduct this research prior to data collection (see attached letter of approval in Appendix H).

Once participants consented to participate, they were asked to complete a demographic information form (see Appendix I). Participants also completed the DT, Jewish Hospital BMTU Distress Measure, Mastery Scale, HADS, Brief RCOPE, and MiLS at the time of their evaluation, which constituted a baseline measurement. Participants again completed the DT, Jewish Hospital BMTU Distress Measure, Mastery Scale, Brief RCOPE, and MiLS the day prior to bone marrow transplantation. Post-transplant, participants completed a specified set of measures each Monday during psychology rounds until they were discharged from the hospital (see table of measures in Appendix J). The first Monday post-transplant, patients were asked to complete the DT, Jewish Hospital BMTU Distress Measure, Mastery Scale, and MiLS. The second Monday post-transplant, participants completed the DT, Jewish Hospital BMTU Distress Measure, and Brief RCOPE. The third Monday post-transplant, participants were again asked to
complete the DT, Jewish Hospital BMTU Distress Measure, Mastery Scale, and MiLS. The fourth Monday post-transplant, participants were asked to again complete the DT, Jewish Hospital BMTU Distress Measure, and Brief RCOPE. This pattern of completing measures was instituted to reduce the burden on participants during their hospitalization. Upon discharge, participants completed the DT, Jewish Hospital BMTU Distress Measure, Mastery Scale, Brief RCOPE, MiLS, and HADS.

Participants were required to complete the measures themselves. If they were unable to do so, caregivers or staff members were permitted to complete the measures, if participants dictated their responses. Throughout data collection, the psychologist and students completed a weekly progress note for each participant during psychology rounds (see weekly progress note in Appendix K). The psychologist and students indicated whether each participant was in isolation and/or began taking medication for the treatment of depression, anxiety, or another mood disorder to better assess the effects of isolation, antidepressants and anxiolytics on levels of distress.

Upon completion, the Jewish Hospital BMTU Distress Screening Measure was copied and the original forms were placed in the medical chart for review by interdisciplinary care team members and incorporated into the patient’s treatment plan. Copies of the Jewish Hospital BMTU Distress Screening Measure, as well as all of the other measures were de-identified and filed in a private, secured office for analysis. Participant names were removed and replaced with identification numbers to ensure confidentiality. The list of participant names corresponding to the assigned identification numbers were also filed in a private, secured office, separate from the copies of the distress measures, demographics forms, and weekly progress notes. The list of participant names was destroyed following completion of data collection. Upon discharge from
the hospital, participant charts were reviewed for additional information potentially related to participant distress, such as duration of isolation periods and infections.
Chapter IV

Proposed Analyses

The primary purpose of this study is to identify a trajectory of distress for BMT inpatients throughout their hospitalization. It is hypothesized that patient distress levels are highest the day prior to BMT, and gradually decrease throughout the hospitalization. This hypothesis will be analyzed with a repeated measures ANOVA, and will consist of three to five assessment points.

Causes of participants’ increased levels of distress will be identified by the Jewish Hospital BMTU Distress Measure, Mastery Scale, MiLS, and Brief RCOPE. Hypotheses related to the Jewish Hospital Distress Screening Measure include: 1. Emotional concerns, as measured by the emotional issues section of the Jewish Hospital Distress Screening Measure positively correlate with patient’s overall distress, as measured by the Jewish Hospital Distress Screening Measure; 2. Spiritual concerns, as measured by the spiritual concerns section of the Jewish Hospital Distress Screening Measure positively correlate with patient’s overall distress, as measured by the Jewish Hospital Distress Screening Measure; 3. Practical concerns, as measured by the practical issues section of the Jewish Hospital Distress Screening Measure, positively correlate with patient’s overall distress, as measured by the Jewish Hospital Distress Screening Measure.; 4. Family concerns, as measured by the family issues section of the Jewish Hospital Distress Screening Measure positively correlate with patient overall distress, as measured by the Jewish Hospital Distress Screening Measure; 5. Physical concerns, as measured by the physical issues section of the Jewish Hospital Distress Screening Measure positively correlate with patient
overall distress, as measured by the Jewish Hospital Distress Screening Measure. These hypotheses are correlational, and will be tested using one-predictor regression equations.

The Mastery Scale will be utilized to assess patients’ perceived level of personal control during BMT. It is hypothesized that personal control, as assessed by the Mastery Scale, negatively correlates with patient overall distress, as assessed by the Jewish Hospital Distress Screening Measure. This hypothesis will also be analyzed using a one-predictor regression equation. The MiLS will be utilized to assess patients’ sense of meaning during BMT. Additionally, the Brief RCOPE will be utilized to assess patients’ religious coping style during BMT. It is hypothesized that patient sense of meaning in life and a positive religious coping style negatively correlates with patient overall distress before, during, and after BMT, as assessed by the Jewish Hospital Distress Screening Measure. This hypothesis will be analyzed through multiple regression.

A secondary aim for this study is to validate the Jewish Hospital Distress Screening Measure for use with BMT inpatients by establishing convergent validity between the DT and the Jewish Hospital Distress Screening Measure, and the HADS and the emotional issues section of the Jewish Hospital Distress Screening Measure. To this end, a Pearson r between the aforementioned measures (i.e., DT and Jewish Hospital Distress Screening Measure, and the HADS and the emotional issues section of the Jewish Hospital Distress Screening Measure) will be calculated.

Additional exploratory analyses will be conducted to assess the ability of demographic variables to predict patient overall distress, as measured by a demographics questionnaire. Lastly, the amount of variance accounted for by patients’ perceived level of social support will be assessed. It is hypothesized that perceived social support, as assessed by a single, face valid
question constructed by the researcher (i.e., "How supported do you feel by your family and friends?") negatively correlates with patient overall distress, as assessed by the Jewish Hospital Distress Screening Measure.
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doi:10.1001/jama.291.19.2335


Bone Marrow Transplantation, 29, 917-925. doi: 10.1038/sj/bmt/1703557


Appendix A

Distress Thermometer

Removed due to Copyright.

This measure is available through National Cancer Comprehensive Network.

http://www.nccn.org/default.aspx
Appendix B

Hospital Anxiety and Depression Scale

Removed due to Copyright.

This measure is available through GL-Assessment.

http://www.gl-assessment.co.uk
Appendix C

Mastery Scale

Removed due to Copyright.

This measure is available through the American Sociological Association (ASA).

http://www.asanet.org/journals/permissions.cfm
Appendix D

Brief RCOPE

Removed due to Copyright.

This measure is available through Religions (Open Access Journal).

www.mdpi.com/journal/religions
Appendix F

Jewish Hospital BMTU Distress Screening Measure

Jewish Hospital BMTU

Please circle the number that describes how much distress you are experiencing today:

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-10</td>
<td>None</td>
</tr>
</tbody>
</table>

- No Distress
- Extreme Distress

Please circle the number that describes how much distress you have experienced in the past week:

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-10</td>
<td>None</td>
</tr>
</tbody>
</table>

- No Distress
- Extreme Distress

Please circle the number that describes how much distress the following issues have caused you in the past week, including today:

**Practical Issues:**

- Concerns about daily care of children:
  - 0-10: None
  - 11-20: Problem

- Housing:
  - 0-10: None
  - 11-20: Problem

- Finances, bills, insurance:
  - 0-10: None
  - 11-20: Problem

- Work, concerns about job:
  - 0-10: None
  - 11-20: Problem

**Family Issues:**

- Worries about children:
  - 0-10: None
  - 11-20: Problem

- Worries about partner, spouse, caregiver:
  - 0-10: None
  - 11-20: Problem

- Conflict in family:
  - 0-10: None
  - 11-20: Problem

**Emotional Issues:**

- Sadness/Depression:
  - 0-10: None
  - 11-20: Severe

- Anxiety/Worry:
  - 0-10: None
  - 11-20: Severe

- Fear:
  - 0-10: None
  - 11-20: Severe

- Boredom:
  - 0-10: None
  - 11-20: Severe

- Loneliness:
  - 0-10: None
  - 11-20: Severe

- Homesickness:
  - 0-10: None
  - 11-20: Severe

**Spiritual Concerns:**

- I feel a sense of meaning and purpose:
  - 0-10: Not at all
  - 11-20: Very Much

- I feel cared for by a Higher Power:
  - 0-10: Not at all
  - 11-20: Very Much

- I feel supported by my spiritual community:
  - 0-10: Not at all
  - 11-20: Very Much

**Physical Issues:**

- I am distressed by the side effects of treatment:
  - 0-10: Not at all
  - 11-20: Extremely

- Eating is a problem:
  - 0-10: Not at all
  - 11-20: Severe

- Pain is a problem:
  - 0-10: Not at all
  - 11-20: Severe

- Fatigue is a problem:
  - 0-10: Not at all
  - 11-20: Severe

Additional problems or concerns:

Administered by: ________________________________
Date: ________________________________
mood disorder. They may also review your medical chart for additional information related to your treatment

4. Risks and Precautions
The following foreseeable risks and discomforts are involved in this study:

There are no foreseeable risks or discomforts involved in your participation in this study. Should any discomfort arise you should contact Dr. Lyn Sontag who is the psychologist on the bone marrow transplant unit at Jewish Hospital or any member of this research team.

5. Benefits
The following benefits may reasonably be expected from this study:

The information we collect from this study will be valuable in your treatment as well as treatment for future bone marrow transplant patients. By assessing your level of distress during hospitalization, and the causes of any discomfort you may feel, we will be better able to meet your needs. Through learning what types of services are needed and when our services can be of most help to meet your needs, we will be better able to meet your needs and the needs of future bone marrow transplant patients throughout their hospitalization. You may obtain results from this study after its completion which can be accomplished by contacting one of the research team members.

6. Alternative Procedures Available
The following alternative procedures are also available should you decide against participating in this study:

Should you choose to not participate in this study, you will still be asked to complete a weekly survey of distress during psychology rounds throughout your hospitalization to aid in your care and your concerns will be referred to the appropriate staff member. Your surveys will still be placed in your medical chart; however, no copies will be made of the surveys and your responses will not be tracked as part of this study. You will still be eligible for all of the services offered by Jewish Hospital, as well as the services provided the psychologist, social worker, and chaplain of this unit regardless of your participation in this study.

7. Right of Refusal
Participation in this study is voluntary. If you refuse to participate, there will be no penalty or loss of any benefit to which you are entitled. If you volunteer to participate in the study, you may withdraw from the study at anytime without penalty or loss of any benefit to which you are entitled.

8. Confidentiality
Your medical records will be treated as confidential. Only authorized personnel will have access to the records. It is possible that an authorized person from the Department of Health & Human Services (DHHS), Food & Drug Administration (FDA) or other federal agency will inspect the records. In all instances except FDA, in the case of a new drug investigation, the FDA does have the right to know your name and this may be revealed to the proper authorities from the FDA if requested to do so. Unauthorized persons will not be permitted to examine your records without your written consent.
9. **Availability of Information:**

We very much appreciate your participation in this study and your willingness to aid us in providing the best services possible. Any questions that you may have concerning any aspect of this study or your rights as a participant in the study will be answered by:

Dr. Lyn Sontag, Psy.D., ABPP (Principle Investigator)
(513) 686-5237
4777 East Galbraith Road
Cincinnati, Ohio 45236
lxsontag@health-partners.org

Ashley Arnott Barroquillo (Associate Investigator)
(513) 686-5237
4777 East Galbraith Road
Cincinnati, Ohio 45236
ash.arnott@gmail.com

The Jewish Hospital of Cincinnati follows a policy of making all decisions concerning financial compensation of medical care for injuries occurring during or caused by participation in biomedical or behavioral research on a case-by-case basis. If you believe you have been injured as a result of any procedure of research, contact Stephen J. Goldberg, M.D., Chairman, The Jewish Hospital Institutional Review Board, (513) 686-5446.

**CONSENT**

I, ____________________________________________, HAVE READ AND UNDERSTAND THE PRECEDING EXPLANATION, AND I CONSENT TO PARTICIPATE IN THE STUDY AS DESCRIBED ABOVE IN SECTION 2 CAPTIONED “OBJECTIVES”. I CONSENT TO THE PROCEDURES DESCRIBED IN SECTION 3 CAPTIONED “PROCEDURES”. I UNDERSTAND THAT I AM FREE TO WITHDRAW WITHOUT PENALTY OR LOSS OF BENEFIT FROM THIS INVESTIGATION AT ANY TIME. SHOULD I WISH TO WITHDRAW I HAVE BEEN ASSURED THAT STANDARD THERAPY FOR MY CONDITION WILL REMAIN AVAILABLE TO ME. I HAVE BEEN INFORMED OF THE PROBABLE CONSEQUENCES OF MY WITHDRAWAL FROM THE STUDY.

SUBJECT: ____________________________________________ DATE: ________________

INVESTIGATOR: ______________________________________ DATE: ________________

WITNESS: ______________________________________ DATE: ________________
Appendix H

Jewish Hospital IRB Approval Document

THE JEWISH HOSPITAL OF CINCINNATI
INSTITUTIONAL REVIEW BOARD
4777 EAST GALBRAITH ROAD
CINCINNATI, OHIO 45236
(513) 686-5446/ FAX (513) 686-5443

DATE: June 8, 2010

TO: Lyn Sontag, M.D.

FROM: Stephen Goldberg, MD
Chairperson, Jewish Hospital Institutional Review Board
FDA #: FWA00002824

RE: Protocol # 10-08

The Jewish Hospital Institutional Review Board reviewed your protocol on
5/18/10, entitled “Trajectory of Distress for Bone Marrow Transplant Inpatients
and Validation of Jewish Hospital BMTU Distress Screening Measure”. The
following action was taken:

X Protocol/Consent Form Approved; Protocol Activated 6/5/10
Protocol/Consent Form Approved for Continuation for one year
Progress Report Approved/Protocol Closed
Notification Received and Noted

Sincerely,

Stephen J. Goldberg, M.D.
Chairman, Institutional Review Committee

Stephenc Goldberg, M.D.
Miriam Warshauer
Waqas Ahmed, M.D.

Chris Heick
Kenneth Washington
Fr. Dale Peterka
Appendix I

Demographics Form

ID #: _________________________________

Date of birth: _________________________

Male or Female (circle one)

Race/Ethnicity:
   a. White/Non-Hispanic
   b. African American
   c. Hispanic
   d. Asian/Pacific Islander
   e. American Indian/Alaska Native
   f. Other ___________________________

Education Level:
   a. Less than high school diploma
   b. High school diploma/GED
   c. Associate degree
   d. Bachelor's degree
   e. Some graduate school
   f. Graduate degree
   g. Other ___________________________

Marital Status:
   a. Single
   b. Married
   c. Life partner
   d. Separated
   e. Divorced
   f. Widowed
   g. Other ___________________________

Total Household Annual Income:
   a. Less than $9,999
   b. $10,000 to $19,999
   c. $20,000 to $29,999
   d. $30,000 to $39,999
   e. $40,000 to $49,999
   f. $50,000 to $59,999
   g. $60,000 to $69,000
   h. $70,000 to $79,999
   i. $80,000 to $89,999
   j. $90,000 to $99,000
   k. $100,000 or above
Number of people currently living in your home: ________________
Number of children under the age of 18 currently living in your home: ________________
Diagnosis: ________________
Date of Admission: ________________
Date of Transplant: ________________
Driving Distance from Jewish Hospital (approximate miles): ________________
Are you currently taking medication for depression, anxiety or another mood disorder?
    Yes or No (circle one)
Who will be your primary source of support (caregiver) during treatment and recovery?

Do you consider yourself a religious/spiritual person?
    Yes or No (circle one)
Will you be receiving an autologous or allogeneic transplant? (Circle one)
## Appendix J

### Table of Measures

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<thead>
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<th>Time</th>
<th>Consent</th>
<th>Demographics</th>
<th>HADS</th>
<th>DT</th>
<th>JHDSM</th>
<th>Mastery</th>
<th>RCOPE</th>
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</table>
Appendix K

Weekly Progress Note

Patient ID Number: ________________________________
Date of Admission: _____________________________  Date of Discharge: _____________________________
Medical Issues / Complications (please indicate the date these occurred):

Admission Measure (check when completed) ____________

Week 1 Measure ____________
Patient in isolation? Yes or No (circle one)
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 2 Measure ____________
Patient in isolation? Yes or No (circle one)
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 3 Measure ____________
Patient in isolation? Yes or No (circle one)
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 4 Measure ____________
Patient in isolation? Yes or No (circle one)
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 5 Measure ____________
Patient in isolation? Yes or No (circle one)
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 6 Measure ____________
Patient in isolation? Yes or No (circle one)
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 7 Measure ____________
Patient in isolation? Yes or No (circle one)
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)
Appendix L

Permission for use of Distress Thermometer

National Comprehensive Cancer Network* 275 Commerce Drive
Fort Washington, PA 19034
Suite 300
215.690.0300
Fax: 215.690.0280
www.nccn.org

April 16, 2010
Lyn Sontag, Psy.D.
Jewish Hospital
4777 East Galbraith Road
Cincinnati, OH 45236

Dear Dr. Sontag:

On behalf of the National Comprehensive Cancer Network (“NCCN”) I am writing to grant you limited one time permission to reproduce the Distress Thermometer Screening Tool FIGURE (DIS-A) from the NCCN 1.2010 Distress Management Guidelines for use with your patients. Permission is granted solely for the purposes described herein which you represent and warrant to be for non-promotional educational use only. The following qualifications also apply to the permission granted by this letter:

1. You agree to include a citation giving full credit to the NCCN for these Guidelines as follows:
   Reproduced with permission from The NCCN 1.2010 Distress Management Clinical Practice Guidelines in Oncology. ©National Comprehensive Cancer Network, 2010. Available at:

2. Permission is for one time use only and expires after one year.

3. You must initial this letter to denote your acceptance of the terms/stipulations in this letter, and fax it back to NCCN at 215-690-0283 to the attention of Nicole Fair.

4. You agree that you will not translate, change, adapt, delete, extract portions, or modify the content of the NCCN 1.2010 Distress Management Guidelines.

5. Permission is for reproduction of the Guidelines in print media only. No Electronic Rights (including CD-ROM and Internet) are granted. Reproduction of the Guidelines into any other medium, including but not limited to electronic media, is explicitly prohibited. You further agree that any reproduction of the Guidelines will include NCCN’s URL address www.nccn.org, to link to the most updated version of the NCCN Distress Management Guideline.

6. Permission is granted for reproduction in the English language only.

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Appendix M

Permission for use of Hospital Anxiety and Depression Scale

Granada Learning

INVOICE TO:
Account No: 124379
Lyn Sontag PsyD
Clinical Psychologist
Jewish Hospital BMTC
4777E Galbraith Road
CINCINNATI
Ohio
45236
United States

DELIVER TO:
Account No: 124379
Lyn Sontag PsyD
Clinical Psychologist
Jewish Hospital BMTC
4777E Galbraith Road
CINCINNATI
Ohio
45236
United States

---

PRO FORMA

Order Processed By: sgie8
Customer Order Number: Sontag130111

Our Order Number: 622804
Order Date: 13 January 2011

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</thead>
<tbody>
<tr>
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</table>

Permission - Dr R P Brough 50% - No VAT
Permission to use 300 administrations of HADS in the dissertation for completion of doctorate in psychology
Support of Ashley Brough
Trajectory of Distress in Bone Marrow
Transplant Patients

---

Final Price £90.00

---

Payment Accepted Via Cheque Credit Card or BACS.

Cheques made payable to Granada Learning Ltd
Bank Swift Code: BARCGB21(T) for international use

---

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Swindon Wiltshire SN2 8EZ
Tel: 01793 516 347 Fax: 01793 501 5357

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Granada Learning Ltd Customer Services
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Techno Trading Estate
Swindon Wiltshire SN2 8EZ
Tel: 0845 602 1937 Fax: 0845 601 5356

VAT No. GB 811 5417 59
Appendix N

Permission for use of Mastery Scale

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References


Appendix O

Permission for use of Brief RCOPE

from Kenneth I Pargament <kpargam@bgsu.edu>
to Ashley Barroquillo <ash.arnott@gmail.com>
date Wed, Sep 8, 2010 at 7:53 AM
subject RE: Brief RCOPE measure
mailed-by bgsu.edu

Dear Ashley:

You have my permission to use the Brief RCOPE. I’ve attached a manual. Let me know if you have any questions. Please keep me posted on your findings.

Best regards,
Ken Pargament
Appendix P

Permission for use of Meaning in Life Scale

from Barb Andersen <andersen.1@osu.edu>
to Ashley Barroquillo <ash.arnott@gmail.com>
date Tue, Sep 7, 2010 at 9:25 AM
subject Re: Meaning in Life Scale
mailed-by osu.edu

No permission needed. Public domain.
Chapter V: Dissertation

Abstract

High levels of distress are common among cancer patients, although few are referred for professional psychosocial care. Leading institutions such as the NCCN strongly recommend routine assessment of distress. There were three primary aims for this study: To establish a trajectory of distress for Bone Marrow Transplant inpatients throughout hospitalization; to determine variables that contribute to patient distress; and, to validate a new screening measure for distress specifically developed for use with BMT inpatients. Eighty-five BMT inpatients participated. No point in the trajectory of hospitalization could be identified as the highest point of distress. The point of lowest distress was at the time of discharge. As hypothesized, emotional, practical, family, physical, perceived level of personal control, meaning of life event, religious coping style, and perceived level of social support significantly contributed to patient distress throughout hospitalization. The Jewish Hospital Bone Marrow Transplant Unit Distress Screening Measure was validated as a screening measure for use with BMT inpatients. The ability to find meaning in life, maintain a positive religious coping style, a perception of personal control, and the support of others were identified as potential protective factors for patients undergoing BMT. Specifically assessing for these factors prior to admission and throughout hospitalization can provide clinicians with a more comprehensive understanding of patient strengths and limitations and help to identify patients who may benefit from additional support throughout BMT.
Trajectory of Distress for Bone Marrow Transplant Inpatients and Validation of Jewish Hospital BMTU Distress Screening Measure

Over the past 40 years, bone marrow transplantation (BMT) has been employed with increasing frequency and success to treat numerous diseases (Moore, 2008). However, the process of BMT can engender a great deal of emotional and physical distress in patients and their families (Lesko, 1994; Stewart & Sugar, 2002). Leading institutions such as the National Comprehensive Cancer Network (NCCN) recognize psychological distress as a significant concern for individuals with cancer and strongly recommend routine assessment of distress (Holland et al., 2010). The recommended initial step in managing distress is administering a self-report measure, such as the Distress Thermometer (Roth, Kornblith, Batel-Copel, Peabody, Scher, & Holland, 1998), to determine the causes of distress including physical, emotional, social, practical, and spiritual concerns.

Indeed, high levels of distress are common among cancer patients (Hoffman, Zevon, D’Arrigo, & Cecchini, 2004; Jacobsen et al., 2005; Trask et al., 2002). As many as one third to over one half of cancer patients report significant distress (Carlson et al., 2004; Lee et al., 2005; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001), although fewer than 10% of these patients are referred for professional psychosocial care (Carlson & Bultz, 2003). Unfortunately, distress is often not recognized by oncology professionals which decreased the opportunity for psychosocial intervention (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Sollner et al., 2001).

Research that seeks to better understand distress among cancer patients at various stages in the illness is crucial as increased levels of distress have been associated with poorer treatment adherence, decreased satisfaction with care, and poorer quality of life (Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000). Few longitudinal studies have investigated the effect of such
psychosocial variables prior to and throughout BMT. Fife et al. (2000) found the period of
greatest distress occurred after hospital admission and before bone marrow infusion, during
which time there was a significant increase in patient anxiety, depression, and uncertainty.
Patients experienced a gradual decline in uncertainty and anger throughout hospitalization, and
both anxiety and uncertainty decreased significantly after discharge from the hospital (Fife et al.,
2000). In contrast, Molassiotis, Van Den Akker, Milligan, Goldman, & Boughton (1996) found
high psychological morbidity was present the day before transplant, but remained elevated
throughout hospitalization and a month after hospital discharge. Interestingly, Fife et al. (2000)
also concluded that the variable most strongly and consistently related to emotional response was
personal control. Likewise, Baker, Marcellus, Zabora, Polland, and Jodrey (1997) found that
personal control, as measured by the Mastery Scale (Pearlin, Menaghan, Leiberman, & Mullan
1981; Pearlin & Schooler, 1978), and dispositional optimism, were predictive of psychosocial
adjustment.

Certainly, religion and spirituality can be valuable resources for individuals with cancer
(Halstead & Fernsler, 1994; Sherman, Simonton, Adams, Vural, & Hanna, 2000), with some
research indicating significant positive correlations between religiosity and enhanced coping, and
more effective adjustment to illness (Sherman & Simonton, 2001). Sherman, Plante, Simonton,
Latif, and Anaissie (2009) sought to further understand the relationship between religious coping
and health–related quality-of-life outcomes throughout the BMT treatment process. As expected,
negative religious coping styles predicted modestly worse outcomes than positive religious
coping styles. In addition, religious or spiritual struggling at the time of stem cell collection
predicted more anxiety and depression, worse emotional well-being, and more transplant-related
contems post-transplant. In a related study, Sherman, Simonton, Latif, Spohn, & Tricot (2005)
reported only negative religious coping, not positive coping, was related to patient outcomes and patients who struggled with religiosity in response to cancer experienced more general distress than patients who did not.

It is also common for patients to engage in reappraisal of the meaning of their lives following cancer diagnosis and treatment, and these experiences may be even more paramount for patients undergoing rigorous treatment regimens such as BMT (Xuereb & Dunlop, 2003). Vickberg et al. (2001) suggested patients’ belief that life has purpose may reduce subjective levels of psychological distress. After validating their Meaning in Life Scale (MiLS), Jim and Andersen (2007) later discovered that meaning in life appears to mediate the relationship between social and physical functioning and distress among cancer survivors.

The support of family and friends, as well as medical and psychosocial care providers, is another important factor in BMT patient outcomes. Research supports the conclusion that social support is predictive of emotional and physical outcomes of BMT. In fact, many studies concluded that social support accounts for part of the variance in emotional and physical recovery and is important for patients before, during, and after hospitalization for BMT (Baker, Zabora, Jodrey, Polland, & Marcellus, 1995; Colon, Callies, Popkin, & McGlave, 1991; Rodrigue, Pearman, & Moreb, 1999; Goetzmann et al. (2007); Hochhausen et al. (2007); Wells, Booth-Jones & Jacobsen, 2009).

As suggested by Fife et al. (2000), additional prospective longitudinal research is needed if effective intervention strategies addressing psychological, emotional, and social complications are to be implemented for patients undergoing BMT. A key step in identifying patient distress is creating effective and efficient tools for assessing distress. Additionally, Sherman et al. (2009) called for future research that examines changes in religiosity over time. Specifically, further
research is needed to determine whether negative religious coping is predictive of psychological distress. Finally, further research into the expected trajectory of distress over the course of hospitalization for BMT can aid psychosocial care providers in offering resources and treatment at the most crucial times.

Past research suggests cancer patients undergoing active treatment, such as BMT, may be among those who experience the most distress (Carlson et al., 2004). The extended hospital stay during transplantation likely adds to distress levels, but also presents a crucial opportunity for psychosocial treatment team members to address patient distress. Current measures of distress are relatively lengthy and were not designed to specifically address the concerns of patients enduring bone marrow transplants.

In response to concerns of BMT inpatients and clinicians that the Distress Thermometer (DT) and Patient Problem List (NCCN, 2003; Ransom, Jacobsen, & Booth-Jones, 2006; Roth et al., 1998) did not adequately assess issues among this specific patient population, Lyn Sontag, Psy.D., ABPP constructed The Jewish Hospital BMTU Distress Screening Measure (JHDSM; see Appendix F). Specifically, the JHDSM adds a separate question about current level of distress and additional inquiries regarding spirituality and religion. In contrast to the Patient Problem List, where relatively few inquiries into emotional concerns exist, patients are given the option of indicating boredom, loneliness, and homesickness on the JHDSM as they are commonly endorsed by BMT patients at Jewish Hospital. Questions about sexual interest/activity and loss of interest in regular activities were not included on the JHDSM as they are irrelevant for this population during hospitalization. Hence, an important aim of the current study was to validate the JHDSM.
Additional measures may be useful in further identifying variables that increase patient distress. For this reason, personal control, sense of meaning in life, and religious coping styles were also assessed in the current study. Unique to this study, the MiLS was utilized to examine change in patient perspective of meaning during the BMT process, as well as the interaction with religious coping and change over time. This study also sought to establish a trajectory of distress as in preceding studies (e.g., Fife et al., 2000; Molassiotis et al., 1996), while assessing a unique combination of variables contributing to distress. Additionally, BMT patient distress levels were assessed more frequently than in past studies (e.g., Ho, Horne, & Szer 2002; Sherman et al., 2009; Wells et al., 2009) to gain a more detailed depiction of a trajectory of distress during transplantation. The researcher believes that data from this study will offer valuable information to the Bone and Marrow Transplant Program at Jewish Hospital and aid in patient care.

It was hypothesized that patient distress levels would be highest the day prior to BMT, as measured by the Distress Thermometer and Jewish Hospital BMTU Distress Screening Measure, and decrease throughout the rest of the hospitalization. It was also hypothesized that emotional, practical, family, and physical concerns, as measured by the JHDSM, and negative religious coping, as measured by the Brief RCOPE, would positively predict patient distress. While spiritual concerns, as measured by the JHDSM, personal control, as measured by the Mastery Scale, and perceived social support were hypothesized to negatively predict patient distress. Sense of meaning in life and positive religious coping style were hypothesized to negatively predict patient distress before, during, and after BMT. Additionally, it was expected that the DT and HADS would establish convergent validity with the JHDSM.
Method

Participants

Eighty-five bone marrow transplant inpatients of Jewish Hospital participated in the current study. Participants included only individuals receiving their first autologous or allogeneic BMT. The most important cell needed for BMT is the hematopoietic stem cell, which can be located in bone marrow, cord blood, or peripheral blood. When an individual uses his/her own cells for transplant it is referred to as an autologous transplant. When the cells are obtained from someone other than the recipient, it is referred to as an allogeneic transplant. Patients who had undergone a previous BMT were not eligible for participation as their expectations regarding the treatment process may have influenced their level of distress. Forty-seven participants (55.3%) reported they planned to receive an autologous transplant, 18 (21.2%) reported they planned to receive an allogeneic transplant, and 20 (23.5%) did not respond to the question. All participants completed data during at least three assessment periods.

Participants were 18 years of age or older and fluent in English. They ranged in age from 25 to 75 years old, with a mean age of 57.15 years (SD = 12.20). Fourteen participants reported living 50 or more miles from the hospital with the furthest living 160 miles away. Twenty-six participants (30.6%) stated they were taking psychotropic medications prior to hospital admission while 58 (68.2%) were not. Sixty-eight participants (80%) identified themselves as religious/spiritual prior to admission, 15 (17.6%) stated they were not religious, and two did not respond. Additional demographic information is presented in Table 1.
Materials

Participants completed the Distress Thermometer (DT; see Appendix A), a single-item, self-report measure of psychological distress (NCCN, 2003; Ransom et al., 2006; Roth et al., 1998). The response format is a Likert scale in the shape of a vertical thermometer ranging from zero (indicating no distress) to 10 (indicating extreme distress). Patients are instructed to indicate their level of distress over the past week, including today. Accompanying the DT is the Patient Problem List consisting of five categories in which patients indicate causes of their distress with a check mark. The distress categories consist of practical, family, emotional, and physical problems, as well as one inquiry regarding spiritual/religious concerns. The NCCN published the DT and Patient Problem List in 2003 to assess levels of distress and identify its causes in cancer patients. Roth et al. (1998) originally pilot tested the DT for use with prostate cancer patients. Roth et al. (1998) found the DT to be an acceptable brief measure of distress and referred patients with scores of five and above for further psychiatric evaluation.

Participants also completed the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; see Appendix B). The HADS is a self-report scale originally constructed for use with medical patients to aid in identifying patients who have experienced symptoms of depression and anxiety over the past week. Participants completing the scale respond to questions regarding their level of tension, interest, fearfulness, ability to laugh, worries, cheerfulness, ability to relax, energy, nervousness, appearance, restlessness, hope, panic, and enjoyment. The HADS consists of 14 items, with a Likert-type response format ranging from zero to three. A score of zero indicates a disconfirming response (i.e., not at all, hardly at all, or only occasionally). Likewise, a score of three indicates an affirmative response (i.e., most of the time, very definitely, and nearly all the time). Items 2, 4, 6, 7, 12, and 14 are reversed scored.
Patients' responses are then totaled resulting in a final score ranging from zero to 21. Those with final scores of zero through seven are considered within the "normal range"; those with scores from eight to 10 are considered "borderline abnormal"; those with scores from 11-21 are considered "abnormal" (Zigmong & Snaith, 1983).

The HADS is widely accepted by patients, clinicians, and researchers, with the vast majority of patients willing to complete the measure (Herrmann, 1997). Internal consistency of the English version of the HADS has been deemed acceptable at 0.80 to 0.93 for the anxiety subscales and 0.81 to 0.90 for the depression subscales. Test-retest reliability for zero to two weeks has been established at 0.84 for anxiety and 0.85 for the depression subscale, dropping to 0.73 and 0.76 respectively between two and six weeks, and 0.70 and 0.70 respectively after six weeks and beyond (Herrmann, 1997). In a review of the literature including 747 articles about the HADS, Bjelland, Dahl, Haug, and Neckelmann (2002) concluded the HADS performed well in assessing symptom severity and identifying cases of anxiety disorders and depression in somatic, psychiatric and primary care patients, and in the general population. The authors also identified the number of factors within the HADS by analyzing past research which utilized factor analyses, the correlations between the subscales, and the internal consistency of the subscales (i.e., Cronbach's alpha). They reported most studies demonstrated two factors which were consistent with the HADS depression and anxiety subscales; correlations between these two subscales varied from .40 to .74. Internal consistency reliabilities were computed for the HADS-D and HADS-A at each administration in the current study. Coefficient alphas for the HADS-D varied from .67 to .90 and for the HADS-A from .68 to .93, indicating internal consistency ranging from acceptable to good. More recently, Vodermaier, Linden, and Siu (2009) reviewed literature relevant to the validation of the HADS in oncology settings, concluding the HADS
demonstrated adequate internal consistency and was sensitive to change in cancer patients.

Internal consistency reliabilities were also computed for the HADS at each administration in the current study. Coefficient alphas were .88, indicating good internal consistency reliability.

Participants also completed the Mastery Scale (see Appendix C), a seven item, self-report measure utilized by Pearlin et al. (1981) to assess the extent to which participants perceive themselves as in control of their lives. The Mastery Scale (Pearlin et al., 1981) utilizes a four-point Likert-type response format, (i.e., strongly agree, agree, disagree, or strongly disagree) with agreement indicating lack of personal control and disagreement indicating personal control. The scale is face valid, consisting of items such as, “I have little control over the things that happen to me”, “I often feel helpless in dealing with the problems in my life”, and “I can do just about anything I really set my mind to do.” Items six and seven are reversed scored.

Participants are given little instruction and are simply asked, “Please circle the response that indicates how strongly you agree or disagree with each statement.” Pearlin et al. (1981) subjected the seven items of the Mastery Scale to factor analysis and test-retest reliability was demonstrated by a statistically significant correlation ($r = .44$) between time one and time two assessments. The authors concluded the relationship between the constructs and indicators remained stable over time, and that error was small and did not significantly influence the stability of their estimates. Pearlin et al. (1981) reported a Cronbach’s alpha of 0.64.

Convergent validity of the Mastery Scale was supported by pairwise correlations with measures believed to measure similar constructs to mastery; in the same way, discriminate validity was supported by the near zero correlations with measures hypothesized to measure constructs other than mastery (Pearlin et al., 1978; Robinson, Shaver, Wrightsman, 1991). Internal consistency
reliabilities were computed for the Mastery Scale at each administration in the current study. Coefficient alphas ranged from .83 to .93, indicating good internal consistency reliability.

Additionally, participants completed the Brief RCOPE (Pargament, Koenig, & Perez, 2000; see Appendix D), a 14 item, self-report measure of religious coping, consisting of two subscales that assess positive and negative religious coping styles. Response options range from one to four (i.e., not at all, somewhat, quite a bit, and a great deal) regarding the frequency with which participants utilize a method of coping with a negative event (in the current study referring to BMT). The first seven items refer to positive religious coping styles including such items as: “Looked for a stronger connection with God,” and “Sought God’s love and care.” The last seven items of the scale refer to negative religious coping styles including such items as: “Wondered whether God had abandoned me,” and “Felt punished by God for my lack of devotion.”

The Brief RCOPE was derived from the original RCOPE which contains 21 subscales, each consisting of five items measuring religious coping. The RCOPE was factor analyzed and two factors emerged, measuring positive and negative patterns of coping. A subset of seven items was selected from each of the factors. Items with the largest factor loadings, items that loaded clearly on only one factor, and items from a variety of subscales were chosen to represent the items of the RCOPE (Pargament et al., 2000). Seven positive and seven negative religious coping items comprise the finalized Brief RCOPE.

Both the positive and negative coping subscales have demonstrated internal consistency and discriminant validity (Pargament et al., 2000). Pargament et al. (1998) reported moderate to high internal consistency for each scale. Two populations were assessed including college students and hospital patients over the age of 55. Cronbach’s alpha coefficient estimates were .90 and .87, and .81 and .69 for the positive and negative scales, respectively, within the two
populations. The positive and negative religious coping scales were significantly positively correlated with each other in both the college and hospital samples, \( r = .17, p < .001 \) and \( r = .18, p < .001 \), respectively. Although significant, this correlation is relatively low, which Pargament et al. (1998) suggests is evidence that the two scales are distinctive. Internal consistency reliabilities were computed for the Brief RCOPE positive and negative scales at each administration in the current study. Coefficient alphas ranged from .95 to .96 for the positive scale, indicating good internal consistency reliability. Coefficient alphas ranged from .71 to .88 for the negative scale, indicating acceptable to good internal consistency reliability.

Participants completed the Meaning in Life Scale (MiLS; see Appendix E), developed by Jim, Purnell, Richardson, Golden-Kreutz, and Andersen (2006), to assess the meaning individuals assign to events in their lives. The MiLS is a self-report instrument that includes 21 items referring to the possible impact of cancer on participants’ lives. Participants are asked to indicate how much they agree or disagree with statements about their lives at the present time. The response format is a six-point Likert scale, with responses ranging from strongly disagree to strongly agree. Example inquiries include, “As a result of my cancer diagnosis and treatment, I do NOT value life as much as I used to,” and “As a result of my cancer diagnosis and treatment, I have found new and more worthwhile goals.” Jim et al. (2006) reported internal consistency of the MiLS as 0.93 for the total score with considerable homogeneity among the items. Two week test-retest reliability was 0.80 for the total measure. The total MiLS score was moderately positively correlated with the Medical Outcomes Study-Short Form used to assess physical and psychological quality of life \( (r = 0.58) \), and negatively correlated with the CES-D assessing symptoms of depression \( (r = -0.58) \) and the POMS assessing psychological distress \( (r = -0.62) \). Internal consistency reliabilities were computed for the MiLS at each administration in the
current study. Coefficient alphas ranged from .92 to .95, indicating good internal consistency reliability.

Finally, patients completed the Jewish Hospital Distress Screening Measure (JHDSM; see Appendix F) which retains the face validity of the DT and Patient Problem List. It also utilizes similar domains of concern as the DT and Patient Problem List, including practical, family, emotional, physical, and spiritual issues. However, the JHDSM has been reorganized and expanded to better fit the needs of BMT inpatients and aid the staff in assisting patients. Internal consistency reliabilities were computed for the JHDSM at each administration.

Coefficient alphas ranged from .486 to .77 for the practical concerns section of the JHDSM indicating unacceptable to good internal consistency reliability. The Cronbach’s alpha for the practical concerns section of the JHDSM at 3 weeks post-transplant was a negative value (-.159) likely due to a small sample size ($n=5$) and small number of items (4). According to Nichols (1999), “Another possibility, most likely with small sample sizes and small numbers of items, is that while the true population covariances among items are positive, sampling error has produced a negative average covariance in a given sample of cases.” Coefficient alphas ranged from .19 ($n=25$) to .76 for the family concerns section of the JHDSM, indicating poor to acceptable internal consistency reliability. Coefficient alphas ranged from .66 to .91 for the emotional concerns section of the JHDSM, indicating adequate to good internal consistency reliability. Coefficient alphas ranged from .79 to 1.00 for the spiritual section of the JHDSM, indicating good internal consistency reliability. Coefficient alphas ranged from .73 to .92 for the physical concerns section of the JHDSM, indicating good internal consistency reliability.
Procedure

Data for the present study was archival and collected from patients on the Bone Marrow Transplant Unit (BMTU) at Jewish Hospital in Cincinnati, Ohio from June, 2010 through February, 2013. Prior to initiating data collection, the study was approved by Jewish Hospital’s Institutional Review Board (IRB; see Appendix I) and reviewed annually throughout data collection. Following data collection, Xavier University’s IRB approved the use of the data for the purposes of this dissertation (see Appendix J).

All bone marrow transplant patients of Jewish Hospital, who met criteria for participation, received information regarding the study during their pre-transplant psychological evaluations. Pre-transplant evaluations occurred approximately two to six weeks prior to hospital admission for BMT. In addition to a verbal introduction to the study, patients received detailed written information. The informed consent form outlined study requirements, including completion of paper and pencil measures, the expected amount of time required to complete measures, the ways in which data would be used (as an indication of need for referral for psychosocial care and research purposes), and rules of confidentiality (see Appendix G).

Participants completed a demographic questionnaire (see Appendix H), the DT, Jewish Hospital BMTU Distress Measure (JHDSM), Mastery Scale, HADS, Brief RCOPE, and MiLS at the time of their initial evaluation, which constituted a baseline measurement. Participants again completed the DT, JHDSM, Mastery Scale, Brief RCOPE, and MiLS the day prior to bone marrow transplantation. Post-transplant, participants completed a specified set of measures each Monday during psychology rounds until they were discharged from the hospital. The first Monday post-transplant, patients were asked to complete the DT, JHDSM, Mastery Scale, and MiLS. The second Monday post- transplant, participants completed the DT, JHDSM, and Brief
RCOPE. The third Monday post-transplant, participants were again asked to complete the DT, JHDSM, Mastery Scale, and MiLS. The fourth Monday post-transplant, participants were asked to again complete the DT, JHDSM, and Brief RCOPE. This pattern of completing measures was instituted to reduce the burden on participants during their hospitalization. Upon discharge, participants completed the DT, JHDSM, Mastery Scale, Brief RCOPE, MiLS, and HADS. Table 2 depicts the dependent measures collected at each time of assessment. Additionally, although out of the scope of this study, the week in which patients entered isolation status and began an antidepressant medication was recorded in weekly progress notes (see Appendix K).

Results

The primary purpose of this study was to identify a trajectory of distress for BMT inpatients throughout their hospitalization. Figure 1 represents the trajectory of distress reported by participants. Table 3 presents mean levels of patient distress for each period of assessment on three dependent variables, respectively: Jewish Hospital Distress Measure Question 1 (JHDSM1), Jewish Hospital Distress Measure Question 2 (JHDSM2), and DT. Originally, the researcher planned to analyze the data using a repeated measures analysis of variance (ANOVA) to evaluate changes in each dependent variable across time. However, due to variations in the number of patients participating at each time of assessment, it was not possible to use a repeated measures ANOVA; therefore, paired samples t-tests were used. Paired samples t-tests indicating statistically significant differences between times of assessment are reported in Table 4. The researcher hypothesized that patient distress levels would be highest the day prior to BMT and decrease throughout hospitalization; however, this hypothesis was not supported as no point in the trajectory could be identified as the highest point of distress. The point of lowest distress, as assessed by JHDSM1, was at the time of discharge. Tables 5-10 provide means and standard
deviations for the Brief RCOPE Positive and Negative Scales, Mi.L.S, Mastery Scale, HADS, and the JHDSM Emotional, Practical, Family, Physical, and Spiritual Variables, respectively.

Another aim of the present study was to identify variables contributing to patient distress. Results indicated emotional factors, as assessed by items 10-15 on the JHDSM, were positively predictive of patient distress, as measured by JHDSM1 (How much distress are you experiencing today?), prior to admission ($r(82) = .692, p < .001$), before transplant ($r(72) = .698, p < .001$), one week post-transplant ($r(71) = .744, p < .001$), two weeks post-transplant ($r(23) = .602, p = .001$), and at discharge ($r(64) = .808, p < .001$). Emotional factors, as assessed by items 10-15 on the JHDSM, were positively predictive of patient distress, as measured by JHDSM2 (How much distress have you experienced over the past week?), prior to admission ($r(81) = .735, p < .001$), before transplant ($r(72) = .730, p < .001$), one week post-transplant ($r(72) = .716 , p < .001$), two weeks post-transplant ($r(23) = .548, p = .005$), and at discharge ($r(65) = .740, p < .001$). The mean JHDSM Emotion score the day before transplant ($M= 16.22, SD= 13.99$) was significantly greater than the mean JHDSM Emotion score at discharge ($M= 11.63, SD= 12.62$), $t(58)= 3.90, p < .001$. Across all times of assessment, there was a restriction of range for mean scores on the JHDSM emotional factors variable. Means ranged from 11.63 to 16.86 (scores can range from 0 to 60).

Spiritual concerns, as assessed by items 16-18 on the JHDSM, were not predictive of patient distress, except for JHDSM1 at time 3 (one week post-transplant, $r(69) = -.258, p = .03$). The number of patients completing measures at three and four weeks post-transplant was too small to allow for interpretation. Across all times of assessment, there was a restriction of range for mean scores on the JHDSM spiritual concerns variable. Means ranged from 20.73 to 26.40 (scores can range from 0 to 30, with higher scores indicating fewer spiritual concerns).
Practical concerns, as assessed by items 3-6 on the JHDSM, were positively predictive of patient distress, as measured by JHDSM1, prior to admission ($r(82) = .537, p < .001$), before transplant ($r(72) = .549, p < .001$), one week post-transplant ($r(72) = .446, p < .001$), two weeks post-transplant ($r(23) = .397, p < .05$), and at discharge ($r(64) = .527, p < .001$). Results indicated practical concerns, as assessed by items 3-6 on the JHSDM, were positively predictive of patient distress, as measured by JHDSM2, prior to admission ($r(81) = .493, p < .001$), before transplant ($r(72) = .529, p < .001$), one week post-transplant ($r(73) = .422, p < .001$), two weeks post-transplant ($r(23) = .438, p = .029$), and at discharge ($r(65) = .444, p < .001$). Across all times of assessment, there was a restriction of range for mean scores on the JHDSM practical concerns variable. Means ranged from 3.00 to 6.52 (scores can range from 0 to 40).

Family concerns, as assessed by items 7-9 on the JHDSM, were positively predictive of patient distress, as measured by JHDSM1, prior to admission ($r(82) = .509, p < .001$) before transplant ($r(72) = .644, p < .001$), one week post-transplant ($r(71) = .532, p < .001$), two weeks post-transplant ($r(23) = .409, p = .042$), and at discharge ($r(64) = .692, p < .001$). Family concerns, as assessed by items 7-9 on the JHSMD, were positively predictive of patient distress, as measured by JHSDM2, prior to admission ($r(81) = .478, p < .001$), before transplant ($r(72) = .480, p < .001$), one week post-transplant ($r(72) = .515, p < .001$), two weeks post-transplant ($r(23) = .464, p = .019$), and at discharge ($r(64) = .641, p < .001$). Across all times of assessment, there was a restriction of range for mean scores on the JHDSM family concerns variable. Means ranged from 1.20 to 5.42 (scores can range from 0 to 30).

Physical concerns, as assessed by items 19-22 on the JHDSM, were positively predictive of patient distress, as measured by JHDSM1, prior to admission ($r(81) = .652, p < .001$), before transplant ($r(72) = .585, p < .001$), one week post-transplant ($r(71) = .775, p < .001$), two weeks
post-transplant \((r(22) = .687, \ p < .001)\) and at discharge \((r(64) = .609, \ p < .001)\). Physical concerns, as assessed by items 19-22 on the JHSDM, were positively predictive of patient distress, as measured by JHSDM2, prior to admission \((r(80) = .586, \ p < .001)\), before transplant \((r(72) = .637, \ p < .001)\), one week post-transplant \((r(72) = .698, \ p < .001)\), two weeks post-transplant \((r(23) = .711, \ p < .001)\) and at discharge \((r(65) = .642, \ p < .001)\). The mean JHDSM Physical score prior to admission \((M = 11.03, SD = 8.72)\) was significantly lower than the mean JHDSM Physical score one week post-transplant \((M = 15.82, SD = 9.71), t(74) = 4.75, p < .001\). Across all times of assessment, there was a restriction of range for mean scores on the JHDSM physical concerns variable. Means ranged from 10.99 to 16.80 (scores can range from 0 to 40).

Hypothesis 7 explored whether personal control, as assessed by the Mastery Scale, was negatively predictive of patient overall distress, as assessed by JHSDM1 and JHSDM2. Personal control was negatively predictive of patient distress, as measured by JHDSM1, prior to admission \((r(82) = -.531, \ p < .001)\), the day before transplant \((r(72) = -.548, \ p < .001)\), one week post-transplant \((r(72) = -.458, \ p < .001)\), and at discharge \((r(64) = -.672, \ p < .001)\). Personal control was negatively predictive of patient distress, as measured by JHDSM2, prior to admission \((r(81) = -.626, \ p < .001)\), before transplant \((r(72) = -.486, \ p < .001)\), one week post-transplant \((r(73) = -.428, \ p < .001)\), and at discharge \((r(65) = -.568, \ p < .001)\). Personal control was not assessed at two or four weeks post-transplant to limit patient burden. Additionally, the sample size of patients completing measures at three weeks post-transplant was too small to allow for interpretation. Across all times of assessment, there was a restriction of range for mean scores on the Mastery Scale. Means ranged from 21.02 to 22.15 (scores can range from 0 to 25).
Hypothesis 8 assessed whether a sense of meaning in life and religious coping style (positive and negative) were predictive of patient overall distress before (pre-admission), during (day before transplant), and after BMT (at discharge). Multiple regression was used to determine if sense of meaning in life and religious coping significantly predicted patient distress (as measured by JHDSM1 *(How much distress are you experiencing today?)*). The variables predicted a significant amount of the variance ($R^2 = .354$, $F(3,75) = 13.717$, $p < .0001$) prior to hospital admission. Sense of meaning in life significantly predicted patient distress ($\beta = -.644$, $t(78) = -6.29, p < .0001$), as did positive religious coping ($\beta = .369$, $t(78) = 3.46, p = .001$). Negative religious coping did not significantly predict patient distress pre-admission ($\beta = -.036$, $t(78) = -.374, p = .710$). The same was true when predicting patient distress over the past week, as measured by JHDSM2 *(How much distress have you experienced over the past week??)*. The regression indicated the variables predicted a significant amount of the variance ($R^2 = .324$, $F(3,74) = 11.801$, $p < .0001$). Sense of meaning in life significantly predicted patient distress ($\beta = -.624$, $t(77) = -5.92, p < .0001$), as did positive religious coping ($\beta = .293$, $t(77) = 2.67, p < .05$). Negative religious coping did not significantly predict patient distress pre-admission ($\beta = -.027$, $t(77) = -2.67, p = .791$).

Multiple regression was also used to determine if sense of meaning in life and religious coping style significantly predicted patient distress (as measured by JHDSM1) the day prior to BMT. The regression indicated the variables predicted a significant amount of the variance ($R^2 = .218$, $F(3,67) = 6.239$, $p = .001$). Sense of meaning in life significantly predicted patient distress ($\beta = -.495$, $t(70) = -4.01, p < .0001$). Positive religious coping did not significantly predict patient distress ($\beta = .246$, $t(70) = 1.98, p = .052$), nor did negative religious coping ($\beta = -.084$, $t(70) = - .749, p = .456$). When predicting patient distress over the past week (as measured by JHDSM2),
the variables predicted a significant amount of the variance \( R^2 = .188, \ F(3,67) = 5.186, \ p < .01 \). Sense of meaning in life significantly predicted patient distress \( \beta = -.448, t(70) = -3.56, \ p < .05 \) the day before transplant. Positive religious coping did not significantly predict patient distress \( \beta = .262, t(70) = 2.06, \ p = .420 \). Negative religious coping significantly predicted patient distress \( \beta = -.092, t(70) = -.81, \ p = .001 \).

Likewise, multiple regression was used to determine if sense of meaning in life and religious coping were significantly predictive of patient distress (as measured by JHDSM1) at discharge. The regression indicated the variables predicted a significant amount of the variance \( R^2 = .356, \ F(3,60) = 11.047, \ p < .0001 \). Sense of meaning in life significantly predicted patient distress \( \beta = -.607, t(63) = -5.17, \ p < .0001 \), as did positive religious coping \( \beta = .368, t(63) = 3.13, \ p < .01 \), and negative religious coping \( \beta = -.241, t(63) = -2.32, \ p < .05 \). When predicting patient distress over the past week (as measured by JHDSM2), results indicated the variables predicted a significant amount of the variance \( R^2 = .192, \ F(2,61) = 4.838, \ p < .01 \). Sense of meaning in life significantly predicted patient distress \( \beta = -.439, t(64) = -3.35, \ p = .001 \) as did positive religious coping \( \beta = .334, t(64) = 2.55, \ p < .05 \). Negative religious coping did not significantly predict patient distress \( \beta = -.157, t(64) = -1.36, \ p = .178 \). The mean MiLS score prior to admission \( M = 80.28, SD = 17.93 \) was significantly lower than the mean MiLS score at discharge \( M = 83.81, SD = 2.30 \), \( t(66) = 2.084, p < .05 \). Across all times of assessment, there was a restriction of range for mean scores on the Brief RCOPE, positive and negative religious coping scales, and the MiLS. Means on the Brief RCOPE positive religious coping scale ranged from 18.91 to 20.14 (scores can range from 0 to 28). Means on the Brief RCOPE negative religious coping scale ranged from 26.39 to 26.77 (scores can range from 0 to 28). Means on the MiLS ranged from 78.89 to 83.81 (scores can range from 14-112).
A secondary aim for this study was to validate the JHDSM for use with BMT inpatients. The DT (Roth et al., 1998) and HADS (Zigmond & Snaith, 1983) were used to establish convergent validity. Specifically, the DT was used to validate the JHDSM1 and JHDSM2 assessing patient distress on the day of assessment and patient distress the week prior to assessment, respectively. The correlation between DT and JHDSM1 was significant prior to admission \((r(77) = .84, \ p < .001)\), before transplant \((r(68) = .84, \ p < .001)\), one week post-transplant \((r(68) = .91, \ p < .001)\), two weeks post-transplant \((r(23) = .78, \ p < .001)\), and at discharge \((r(62) = .79, \ p < .001)\). The correlation between DT and JHDSM1 was not significant three weeks post-transplant \((r(3) = .77, \ p = .132)\). The correlation between DT and JHDSM2 was significant prior to admission \((r(76) = .82, \ p < .001)\), before transplant \((r(68) = .86, \ p < .001)\), one week post-transplant \((r(69) = .88, \ p < .001)\), two weeks post-transplant \((r(23) = .74, \ p < .001)\), three weeks post-transplant \((r(3) = .93, \ p < .05)\), and at discharge \((r(63) = .86, \ p < .001)\).

The HADS was used to provide convergent validity with the emotional concerns section of the JHDSM (questions 10-15). The correlation between the HADS and JHDSM questions 10-15 was significant prior to admission \((r(83) = .76, \ p < .001)\) and at discharge \((r(60) = .67, \ p < .001)\). Patients were only asked to complete the HADS prior to hospital admission and at discharge. The mean HADS score prior to admission \((M = 10.26, \ SD = 6.11)\) was significantly greater than the mean HADS score at discharge \((M = 8.53, \ SD = 6.82)\), \(t(61) = 2.554, \ p = .013\).

Additional exploratory analyses were conducted for levels of distress, as measured by JHDSM1, JHDSM2, and DT based on demographic information collected from patients prior to hospitalization. Specifically, univariate analyses of variance and a series of \(t\)-tests were conducted. There were no statistically significant differences in levels of distress at any of the time of assessment when comparing men and women, races, or participant groups divided by
annual income. There were no statistically significant differences between patients receiving an allogeneic versus autogeneic transplant. Likewise, there were no significant differences in distress levels based on patients’ cancer diagnosis.

Although it was not one of the principle intentions of this study, perceived social support was assessed through the use of a single, face-valid question constructed by the researcher, *How supported do you feel by your family and friends?* Perceived social support was significantly negatively predictive of patient distress (as assessed by JHDSM1) the day before transplant ($r(70) = -.331, p = .005$), 1 week post-transplant ($r(68) = -.353, p = .003$), and at discharge ($r(61) = -.440, p < .001$). Perceived social support was not significantly negatively predictive of patient distress (as assessed by JHDSM1) prior to admission ($r(80) = -.186, p = .094$), two weeks post-transplant ($r(23) = -.233, p = .262$), or three weeks post-transplant ($r(3) = -.612, p = .272$).

**Discussion**

**Trajectory of Distress**

A primary purpose of this study was to determine a trajectory of distress throughout hospitalization for bone marrow transplant inpatients. Based upon previous research (Fife et al., 2000; Meyers et al., 1994; Molassiotis, Van Den Akker, Milligan, Goldman, & Boughton, 1996), the researcher hypothesized that the time of greatest patient distress would occur the day before transplant and decrease throughout hospitalization. However, the findings of this study did not support this hypothesis. Significant differences in distress levels existed only when each time of assessment was compared to discharge (as assessed by JHDSM1), with the lowest point of distress occurring at discharge. Apparent increases in distress occurred on the JHDSM2 and DT at three weeks post-transplant, but differences were not meaningful due to a small sample size ($n=5$).
Results of the present study also differed from a study by Molassiotis et al. (1996) in which high psychological morbidity was present the day before transplant and remained elevated throughout hospitalization. More consistent with the results of the current study, Meyers et al. (1994) found that 40% of BMT patients endorsed high levels of anxiety prior to transplantation; however, their anxiety decreased significantly during hospitalization and was lowest at discharge. They attributed decreasing anxiety to an expected and transient reaction to the anticipation of transplant. Conversely, the authors reported significant increases in depression throughout hospitalization. Increasing depression was attributed to possible perceived loss of control.

Interestingly, with the DT used as the dependent variable, distress at one week post-transplant and discharge represented the only statistically significant difference in level of distress on that measure. The significant decline in level of distress, as indicated by scores on the JHDSM1, was not consistent with levels of distress reported on the JHDSM2 or the DT across time and may be due to the wording of the dependent variables. The JHDSM1 inquires about the patients’ level of distress “today,” whereas the JHDSM2 asks patients to consider their level of distress “over the past week,” and the DT asks patients to consider their level of distress “over the past week including today.” Patients may find it more difficult to accurately assess their level of distress when trying to recall the past week, as well as evaluate their level of distress for the past week including today. For this reason, a preferred method of assessing distress may be to ask patients to indicate their current level of distress and distress over the past week separately, as is done on the JHDSM.
A cut-off score of five or above on the DT may indicate psychological distress as indicated by Roth et al. (1998). In the present study, mean scores on the DT reached this level only at three weeks post-transplant, with a sample size of only five patients. This suggests a relatively low level of patient distress throughout hospitalization. Likewise, mean scores on the HADS prior to admission barely broached the abnormal range and mean scores at discharge barely reached borderline abnormal according to the interpretation guidelines recommended by Zigmong and Snaith (1983). Additionally, patients reported limited emotional concerns in the current study, as assessed by JHDSM Emotional Concerns subsection (questions 10-15).

It appears participants in the current study did not endorse a high degree of psychological distress throughout hospitalization for BMT, which likely accounts for the decreased variability in distress during the study. Furthermore, over 30% of participants reported they were taking psychotropic medications for the treatment of anxiety, depression, or a mood disorder prior to hospital admission, which may have tapered distress in those patients during hospitalization. In the current study, different measures were utilized to assess distress than in past research which may account for some of the discrepancies. Varying procedures of the hospitals in which the studies were conducted, such as when periods of isolation are enforced, may also account for varying trajectories of distress between studies. Differences may also exist in the amount of education patients receive about the process of bone marrow transplantation prior to hospitalization at various institutions.

A concerted effort is made at the hospital where the current study was conducted to educate patients and their families about what they can expect prior to admission for BMT. Fife et al. (2000) postulated that BMT patients may have increased levels of distress prior to transfusion due to uncertainty. Efforts to educate patients may result in patients feeling more
prepared and may be especially beneficial in curbing distress before, and during hospitalization. Jewish Hospital also employs a psychologist, social worker, and chaplain to serve the Bone Marrow Transplant Unit which are key resources for patients. It is important to note that participants who were willing and able to continue participation in the study may have experienced fewer complications throughout hospitalization than those who declined to participate or terminated their participation.

In the current study, there was little change in mean Brief RCOPE scores over time. Past researchers have reported similar results. Sherman et al. (2009) examined the religious coping styles of Multiple Myeloma patients and found little change in coping styles over time, although negative religious coping predicted modestly worse outcomes (including increased patient distress) than positive religious coping. Furthermore, Sherman et al. (2005) reported modest findings indicating only negative religious coping was predictive of negative patient outcomes in Multiple Myeloma patients undergoing autologous transplants.

Though personal control, as measured by the Mastery Scale, was a significant predictor of patient distress over time in the current study, little change was found in the mean participant score throughout hospitalization. Interestingly, despite findings from Fife et al. (2000) that personal control was the variable most strongly and consistently associated with emotional response, mean scores of personal control were comparable to the current study and demonstrated little variability. It is difficult to interpret the mean participant scores of the MiLS due to lack of normative data for this population.
Variables Significantly Contributing to Patient Distress Throughout Hospitalization

Another important goal of this study was to identify variables that significantly contributed to patient distress. Practical, family, emotional, spiritual, and physical concerns were assessed by the Jewish Hospital BMTU Distress Screening Measure. Other variables hypothesized to significantly predict patient distress were personal control, as assessed by the Mastery Scale, religious coping, as assessed by the Brief RCOPE, the meaning assigned to the life event, as assessed by the Meaning in Life Scale, and social support, as assessed by a single, face-valid question constructed by this author. As hypothesized, practical, family, emotional and physical concerns were predictive of patient distress prior to, and throughout hospitalization. Interestingly, spiritual concerns were not predictive of distress (using JHDSM1 as the dependent variable) except one week post-transplant when spiritual concerns were negatively correlated with patient distress. Because the spiritual concerns section of the JHDSM are reversed scored, higher numbers indicate a positive religious/spiritual experience and were indicative of less distress one week post-transplant. Although spiritual concerns, as assessed by the JHDSM, did not predict patient distress except at one week post-transplant, 68 (80%) participants indicated that religion/spirituality was important to them prior to admission; only 15 participants (17.6%) stated that it was not. This may indicate a lack of religious/spiritual concerns throughout hospitalization in this sample. Indeed, it appears patients reported few concerns related to their religion/spirituality on the JHDSM. Inquiries into religious/spiritual concerns were included on the JHDSM as a means of alerting staff to the need for a referral to a chaplain, and can continue to be useful in this way.
Personal Control

Personal control, as assessed by the Mastery Scale, was hypothesized to negatively predict patient distress, as assessed by JHDSM1 and JHDSM2. As expected, as a sense of personal control increased, patient distress decreased prior to admission, the day before transplant, one week post-transplant, and at discharge. Fife et al. (2000) concluded that the variable most strongly and consistently related to emotional response was personal control. In concordance with Fife et al. (2000), Baker, Marcellus, Zabora, Polland, and Jodrey (1997) also found that personal control, as measured by the Mastery Scale, along with dispositional optimism, was predictive of psychosocial adjustment.

Meaning in Life and Religious Coping

An important contribution of this study was the assessment of whether meaning in life and religious coping predicted patient distress throughout hospitalization. Researchers have recently become interested in the influence of religiosity and spirituality on health outcomes (e.g., Sherman, Simonton, Latif, Spohn, & Tricot, 2005). As recognized by Pargament, Koenig, and Perez (2000), religious coping encompasses a wide display of responses to illness and stress, including efforts at meaning, control, comfort, and life transformation. Stefanek, McDonald, and Hess (2005) ascertained that studies investigating the impact of religion and spirituality on quality of life are “decidedly mixed,” with research specifically focusing on the role of religion and spirituality on cancer outcomes being too sparse to draw decisive conclusions. Previous studies (Sherman et al., 2009; Sherman & Simonton, 2001; Sherman, Simonton, Plante, Moody, & Wells, 2001) found little change in religious coping styles over time, and only negative coping styles impacted distress levels. More positive religious coping was not related to better health
outcomes. This was not the case in the current study as positive religious coping style appeared to play a more dominant role in predicting distress than negative religious coping.

Meaning in life is an important and multi-faceted construct for humans, referring to the value and purpose placed on one’s life that may also encompass life goals and spirituality (Jim, Purnell, Richardson, Golden-Kreutz, & Andersen, 2006). Theorists, such as Viktor Frankl (1963) have proposed that humans instinctively seek meaning and fulfillment in their lives. Particularly intriguing, are the ways in which people find meaning in the midst of stressful and negative events. Life changing events, such as a diagnosis of cancer, may prompt changes in one’s previously held beliefs of meaning in life (Jim et al., 2006; Park & Folkman, 1997).

Results of the present study found sense of meaning in life and positive religious coping significantly predicted patient distress prior to hospital admission when patients were asked to report their current level of distress (JHDSM1), as well as their distress over the past week (JHDSM2). However, the day prior to BMT, only meaning in life significantly predicted patient distress, as assessed by JHDSM1. When asked about distress over the past week, both meaning in life and negative religious coping significantly predicted patient distress. At discharge, sense of meaning in life, positive, and negative religious coping significantly predicted patient distress when asked about current level of stress; when patients were asked to indicate their level of distress over the past week, only meaning in life and positive religious coping were significant.

Sense of meaning in life was a more consistent predictor of patient distress than religious coping style, and predicted distress at each time of assessment. Additionally, positive religious coping style appeared to be a more consistent predictor of patient distress than a negative religious coping style throughout hospitalization for BMT. Positive religious coping style predicted distress at each time of assessment with the exception of the day prior to BMT.
Negative religious coping style, on the other hand, only predicted current level of distress at discharge and distress over the past week the day before BMT. Interestingly, religious/spiritual concerns on the JHDSM were also largely insignificant in predicting distress throughout hospitalization despite the majority of patients indicating religion/spirituality was important to them prior to admission. It is likely that sense of meaning in life and positive religious coping style overlap to some degree. Together, these variables probably account for more of the variance in distress than negative religious coping. Given the lack of variability in means across the dependent variables, it appears the patients did not waiver in their assessment of personal meaning, religious, or spiritual beliefs throughout the process of BMT. However, given the consistency of self-report, especially in meaning for patient distress, patients who do wavier in their beliefs may be more likely to report a higher level of distress. It is important for psychosocial providers to be aware of such tendencies, as these patients may require more support and interventions.

Given these findings, personal control, meaning in life, and positive religious coping are likely to serve as important protective factors for BMT patients during hospitalization. Of note, Visser, Garssen, and Vingerhoets (2010), in a review of the literature, held that authors who utilized the MiLS likely discovered a negative relationship between meaning in life and psychological distress because the scale contains several items that refer to positive affect, which is related to well-being. Visser et al. (2010) cautioned researchers to recognize the overlap of constructs within measures like the MiLS and encourage future research in the areas of spirituality and meaning in life to better understand the effect of both for cancer patients.
Social Support

Results of the current study indicate perceived social support was significantly predictive of patient distress the day before transplant, one week post-transplant, and at discharge, which likely represent periods of greater reliance on others for patients. Perceived social support was not significantly predictive of distress prior to admission or at two or three weeks post-transplant. In contrast, Meyer et al. (1994) determined that presence or absence of social support was not correlated with depression. Fife et al. (2000) found perceived support from family and friends remained constant throughout hospitalization.

Validation of JHDSM

A secondary aim for this study was to validate the Jewish Hospital BMTU Distress Screening Measure (JHDSM) for use with BMT inpatients. The Distress Thermometer (DT; Roth et al., 1998) and Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) were used to establish convergent validity. Specifically, the DT was used to validate the JHDSM1 and JHDSM2 assessing patient distress on the day of assessment and patient distress the week prior to assessment, respectively. Correlations were statistically significant at all points of assessment, with the exception of three weeks post-transplant when the sample size was too small to interpret. The high correlations between the DT and JHDSM indicate the JHDSM is an equivalent measure for assessing distress. Furthermore, the current study justifies the use of the JHDSM over the DT with BMT inpatients since it was specifically designed for this population.

Demographic Variables

Previous studies have suggested that among cancer patients, women, people of minority status, and those with lower incomes may be more susceptible to high levels of distress (Carlson et al., 2004; Jacobsen et al., 2005). However, among persons in the current sample, there were no
statistically significant differences in level of distress when comparing participants on such demographic variables. The researcher is uncertain why there were no differences between these demographic groups in the current study; however, the current sample was fairly homogenous with only 7.1% of participants indicating they were an ethnic minority. Interestingly, participants were also relatively well educated; over half reported they had an associate’s degree or higher. Only 5.9% of participants reported less than a high school education.

Consistent with Fife et al. (2000)’s findings that few significant differences exist between those receiving allogeneic transplants and those receiving autologous transplants, no differences in type of transplant on patient distress were found in the current study. These results are similar to those of Jenkins, Linnington, and Whittaker (1991), Somerfield and Curbow (1992), and Baker et al. (1994); all of which concluded there was no relationship between type of BMT and adjustment or physical symptomatology.

Clinical Implications

The current study seized the crucial opportunity presented during hospitalization to assess and assist BMT patients with psychological distress. This study also added a validated measure of distress specifically designed for use with BMT inpatients to the existing literature. The primary clinical implication of this study was to provide useful information to hospital staff in determining periods of vulnerability to enhance psychosocial intervention when appropriate. Patients reported relatively consistent levels of distress throughout hospitalization with the lowest level reported at discharge. This trajectory of distress suggests the need for psychosocial support does not vary throughout hospitalization. It is also important for staff to understand the variables contributing to distress during hospitalization (i.e., emotional, practical, family, physical concerns, perceived level of personal control, meaning of the life event, religious coping
style, and perceived level of social support). With the awareness of variables frequently relating to distress, staff can be better equipped to provide necessary referrals and interventions.

Perceived social support was predictive of patient distress at crucial times throughout the BMT process, including the day prior to transplant and one week post-transplant, when many patients reported their highest levels of distress, and at discharge when patients were preparing to return home and would require care. Patients who do not perceive a high level of social support during these crucial times are more likely to need additional support from psychosocial providers.

Unique to this study, the MiLS was used to examine change in patient perspective of meaning during the BMT process. The results were compelling in establishing the importance of the meaning of the event (i.e., cancer diagnosis and treatment) as a contributor to patient distress. The ability to find meaning in life, maintain a positive religious coping style, a perception of personal control, and the support of others were identified as potential protective factors for patients undergoing BMT. Specifically assessing for these factors prior to admission to the hospital can provide clinicians with a more comprehensive depiction of patient strengths and limitations and help to identify patients who may require additional support throughout BMT.

The Jewish Hospital BMTU Distress Screening Measure was designed and validated to assess the numerous causes of distress within BMT inpatients including emotional, spiritual, practical, familial and physical concerns. All variables were significantly predictive of patient distress, with the exception of spiritual concerns. However, asking patients to identify spiritual concerns likely remains clinically useful in alerting providers to the possible need of chaplain services throughout hospitalization. Utilization of additional measures during psychology rounds may be useful in identifying other contributors to patient distress, including perception of
personal control (i.e., the Mastery Scale), meaning in life (MiLS), social support, and religious coping style (Brief RCOPE) as these factors were found to significantly predict patient distress throughout hospitalization.

Limitations

There are limitations of the current study which should be considered when interpreting the results. First, it was not possible to obtain a complete data set from each participant. At times, patients were too ill to complete measures or discontinued participation in the study due to worsening health or death. As previously stated, a selection bias inherently exists in that patients who are faring the best throughout BMT are the most likely to complete the research protocol. It is also likely that patients in this sample may be more highly educated than the BMT patient population. Over 40% of patients who participated in this study reported having an associate’s degree or higher level of education. Less than 6% of participants reported having less than a high school education. Participants represented a specific subset of the population which may account for the lack of significant differences in distress levels across demographic variables. Across means for the Brief RCOPE (positive and negative coping styles), MiLS, Mastery Scale, JHDSM Emotion, Practical, Family, Physical, and Spiritual variables, there was limited variability and a clear restriction of range. These findings speak to the overall lack of reported distress among the sample and may also be indicative of a ceiling effect.

Furthermore, patients did not complete all measures at all times of assessment to lessen patient burden. Participant data was only included in the data analysis if he/she completed assessments at three or more times. It was also difficult to get all patients to complete the final set of measures on the day of discharge due to varying times of discharge. Therefore, it was not
uncommon for patients to complete the final measures during their next follow-up visit post-discharge.

**Future Research**

More research is needed regarding the impact of religious coping throughout the BMT process. Specifically, more information regarding the impact of negative religious coping styles would be beneficial in determining whether religious coping is a protective factor that serves to lessen distress or contributes to patient distress. Future research may also investigate the impact of perceived support from psychosocial providers on patient distress. Perhaps, a perceived lack of social support and negative religious coping (when a patient indicated he/she was previously religious) are better predictors of distress than positive social support or religious coping. As positive religious coping and meaning in life were identified as likely protective factors in the current study, appropriate interventions for patients who do not identify as religious or spiritual prior to hospitalization for BMT should be considered. Future research might investigate the impact of introducing mindfulness techniques to BMT patients prior to or during hospitalization.

While out of the scope of the current study, research investigating the impact of additional factors, such as isolation of patients to protect them from infection, the impact of psychotropic medications, and the impact of delayed discharge due to complications would be useful. Although no significant differences in level of distress between allogeneic and autologous BMT patients were found in this study, it would be of potential interest to examine longitudinal differences following hospital discharge. Due to the risk of graft-versus-host disease, patients who receive an allogeneic transplant may report increased levels of distress after hospitalization when compared to patients who receive an autologous transplant.
References


Table 1

Demographic Characteristics of Participants (N= 85)

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Table 1, continued

*Demographic Characteristics of Participants (N = 85)*

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Table 2

Measures Completed at Each Time of Assessment

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Note. HADS = Hospital Anxiety and Depression Scale, DT = Distress Thermometer, JHDSM = Jewish Hospital BMTU Distress Screening Measure, Mastery = Mastery Scale, RCOPE = Brief RCOPE, MiLS = Meaning in Life Scale
Figure 1

![Graph showing distress over time with different markers representing different groups: DT, JHDSM1, JHDSM2.](image)

*Note.* Number of participants varied at each time of assessment. *n* at time 1 = 84; *n* at time 2 = 74; *n* at time 3 = 74; *n* at time 4 = 25; *n* at time 5 = 5; *n* at time 6 = 66
Table 3

Means and Standard Deviations for Jewish Hospital BMTU Distress Screening Measure Question 1, Jewish Hospital BMTU Distress Screening Measure Question 2, and Distress Thermometer

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<td>Time 1 Pre-admission</td>
<td>84</td>
<td>2.58 (2.64)</td>
<td>83</td>
<td>3.63 (2.81)</td>
<td>80</td>
<td>3.32 (2.72)</td>
</tr>
<tr>
<td>Time 2 Day before transplant</td>
<td>74</td>
<td>3.03 (2.75)</td>
<td>74</td>
<td>3.39 (2.86)</td>
<td>71</td>
<td>3.44 (2.73)</td>
</tr>
<tr>
<td>Time 3 1 week post-transplant</td>
<td>74</td>
<td>3.39 (2.93)</td>
<td>75</td>
<td>3.95 (2.87)</td>
<td>71</td>
<td>3.98 (3.00)</td>
</tr>
<tr>
<td>Time 4 2 weeks post-transplant</td>
<td>25</td>
<td>2.68 (1.97)</td>
<td>25</td>
<td>4.00 (3.03)</td>
<td>25</td>
<td>3.36 (2.72)</td>
</tr>
<tr>
<td>Time 5 3 weeks post-transplant</td>
<td>5</td>
<td>2.40 (.89)</td>
<td>5</td>
<td>5.20 (2.77)</td>
<td>5</td>
<td>4.40 (3.36)</td>
</tr>
<tr>
<td>Time 6 Discharge</td>
<td>66</td>
<td>1.65 (2.38)</td>
<td>67</td>
<td>3.13 (2.77)</td>
<td>5</td>
<td>2.71 (2.80)</td>
</tr>
</tbody>
</table>

Note. No patients completed questionnaires for the original “Time 6” (4 weeks post-transplant), resulting in Time 6 representing discharge from the hospital. Higher numbers indicate higher levels of distress. JHDSM1 = Jewish Hospital Distress Measure Question 1, How much distress are you experiencing today? JHDSM2 = Jewish Hospital Distress Measure Question 2, How much distress have you experienced over the past week? DT = Distress Thermometer, How much distress have you been experiencing over the past week including today?
Table 4

*T-Tests Indicating Significant Differences between Times of Assessment*

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Time Period</th>
<th>Time Period</th>
<th>n</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>JHDSM1 T1</td>
<td>2.64 (2.67)</td>
<td>T6</td>
<td>65</td>
<td>3.13</td>
<td>64</td>
<td>.003</td>
</tr>
<tr>
<td></td>
<td>2.75 (2.72)</td>
<td>T6</td>
<td>57</td>
<td>4.02</td>
<td>56</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>JHDSM1 T3</td>
<td>3.15 (2.85)</td>
<td>T6</td>
<td>61</td>
<td>4.74</td>
<td>60</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>2.95 (2.01)</td>
<td>T6</td>
<td>20</td>
<td>2.30</td>
<td>19</td>
<td>.033</td>
</tr>
<tr>
<td>JHDSM1 T5</td>
<td>2.25 (0.96)</td>
<td>T6</td>
<td>4</td>
<td>7.00</td>
<td>3.00</td>
<td>.006</td>
</tr>
<tr>
<td>DT</td>
<td>3.80 (3.08)</td>
<td>T6</td>
<td>59</td>
<td>3.34</td>
<td>58</td>
<td>.001</td>
</tr>
</tbody>
</table>

*Note.* Higher numbers indicate higher levels of distress. JHDSM1 = Jewish Hospital Distress Measure Question 1, *How much distress are you experiencing today?* JHDSM2 = Jewish Hospital Distress Measure Question 2, *How much distress have you experienced over the past week?* DT = Distress Thermometer, *How much distress have you been experiencing over the past week including today?* Mean values do not correspond to those in Table 2 because the sample sizes differed based on the number of patients who completed the measures at each time.
Table 5

Means and Standard Deviations for Brief RCOPE Positive Scale and Brief RCOPE Negative Scale

<table>
<thead>
<tr>
<th>Time</th>
<th>n</th>
<th>Brief RCOPE Positive Scale M (SD)</th>
<th>n</th>
<th>Brief RCOPE Negative Scale M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 Pre-admission</td>
<td>82</td>
<td>19.05 (7.04)</td>
<td>82</td>
<td>26.39 (3.32)</td>
</tr>
<tr>
<td>Time 2 Day before transplant</td>
<td>73</td>
<td>20.14 (7.16)</td>
<td>72</td>
<td>26.63 (2.71)</td>
</tr>
<tr>
<td>Time 4 2 weeks post-transplant</td>
<td>23</td>
<td>18.91 (7.89)</td>
<td>23</td>
<td>27.22 (1.86)</td>
</tr>
<tr>
<td>Time 6 Discharge</td>
<td>66</td>
<td>20.06 (7.76)</td>
<td>65</td>
<td>26.77 (2.94)</td>
</tr>
</tbody>
</table>

Note. Higher numbers on the Brief RCOPE positive scale are indicative of a positive religious coping style, with a possible range in scores of 7 to 28. Likewise, higher numbers on the Brief RCOPE negative scale are indicative of a negative religious coping style, with a possible range in scores of 7-28.
Table 6

Means and Standard Deviations for Meaning in Life Scale and Mastery Scale

<table>
<thead>
<tr>
<th>Time</th>
<th>n</th>
<th>Meaning in Life Scale M (SD)</th>
<th>n</th>
<th>Mastery Scale M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 Pre-admission</td>
<td>85</td>
<td>78.89 (17.47)</td>
<td>85</td>
<td>21.02 (3.89)</td>
</tr>
<tr>
<td>Time 2 Day before transplant</td>
<td>75</td>
<td>82.25 (19.64)</td>
<td>75</td>
<td>21.45 (3.94)</td>
</tr>
<tr>
<td>Time 3 1 week post-transplant</td>
<td>76</td>
<td>81.34 (19.84)</td>
<td>76</td>
<td>21.22 (4.20)</td>
</tr>
<tr>
<td>Time 5 3 weeks post-transplant</td>
<td>5</td>
<td>83.40 (16.33)</td>
<td>5</td>
<td>21.20 (3.96)</td>
</tr>
<tr>
<td>Time 6 Discharge</td>
<td>67</td>
<td>83.81 (18.82)</td>
<td>67</td>
<td>22.15 (4.05)</td>
</tr>
</tbody>
</table>

Note. Higher numbers on Meaning in Life Scale indicate more positive meaning assigned to cancer diagnosis and treatment. Scores can range from 14 to 112. Higher numbers on Mastery Scale indicate a higher degree of perceived control. Scores can range from 5 to 25.
Table 7

*Means and Standard Deviations for Hospital Anxiety and Depression Scale*

<table>
<thead>
<tr>
<th>Time</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1</td>
<td>85</td>
<td>10.59 (6.14)</td>
</tr>
<tr>
<td>Pre-admission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 6</td>
<td>62</td>
<td>8.53 (6.82)</td>
</tr>
<tr>
<td>Discharge</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Higher numbers on Hospital Anxiety and Depression Scale indicate a higher level of depression and anxiety.
Table 8

*Means and Standard Deviations for Jewish Hospital Distress Measure Emotion Variables and Practical Variables*

<table>
<thead>
<tr>
<th>Time</th>
<th>$n$</th>
<th>JHDSM Emotion Variables $M$ (SD)</th>
<th>$n$</th>
<th>JHDSM Practical Variables $M$ (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 Pre-admission</td>
<td>85</td>
<td>12.11 (11.25)</td>
<td>85</td>
<td>6.52 (6.39)</td>
</tr>
<tr>
<td>Time 2 Day before transplant</td>
<td>75</td>
<td>16.86 (13.44)</td>
<td>75</td>
<td>5.89 (6.75)</td>
</tr>
<tr>
<td>Time 3 1 week post-transplant</td>
<td>75</td>
<td>16.09 (12.84)</td>
<td>76</td>
<td>3.43 (5.36)</td>
</tr>
<tr>
<td>Time 4 2 weeks post-transplant</td>
<td>25</td>
<td>14.44 (10.58)</td>
<td>25</td>
<td>3.20 (5.09)</td>
</tr>
<tr>
<td>Time 5 3 weeks post-transplant</td>
<td>5</td>
<td>14.40 (7.83)</td>
<td>5</td>
<td>3.00 (4.00)</td>
</tr>
<tr>
<td>Time 6 Discharge</td>
<td>67</td>
<td>11.63 (12.16)</td>
<td>67</td>
<td>3.28 (4.77)</td>
</tr>
</tbody>
</table>

*Note. For JHDSM Emotion Variables, higher numbers are indicative of increased emotional concerns (i.e., depression, anxiety, fear, boredom, loneliness, homesickness). Scores range from 0 to 60. For JHDSM Practical Variables, higher numbers are indicative of increased practical concerns (i.e., care of children, housing, finances, work concerns). Scores range from 0 to 40.*
Table 9

Means and Standard Deviations for Deviations for Jewish Hospital Distress Measure Family Variables and Physical Variables

<table>
<thead>
<tr>
<th>Time</th>
<th>n</th>
<th>JHDSM Family Variables M (SD)</th>
<th>n</th>
<th>JHDSM Physical Variables M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 Pre-admission</td>
<td>85</td>
<td>5.42 (5.62)</td>
<td>84</td>
<td>10.99 (8.57)</td>
</tr>
<tr>
<td>Time 2 Day before transplant</td>
<td>75</td>
<td>5.14 (5.60)</td>
<td>75</td>
<td>11.70 (8.76)</td>
</tr>
<tr>
<td>Time 3 1 week post-transplant</td>
<td>75</td>
<td>4.79 (6.06)</td>
<td>75</td>
<td>15.82 (9.71)</td>
</tr>
<tr>
<td>Time 4 2 weeks post-transplant</td>
<td>25</td>
<td>2.68 (3.17)</td>
<td>24</td>
<td>16.17 (11.30)</td>
</tr>
<tr>
<td>Time 5 3 weeks post-transplant</td>
<td>5</td>
<td>1.20 (1.10)</td>
<td>5</td>
<td>16.80 (11.92)</td>
</tr>
<tr>
<td>Time 6 Discharge</td>
<td>67</td>
<td>3.68 (5.40)</td>
<td>67</td>
<td>12.87 (9.90)</td>
</tr>
</tbody>
</table>

Note. For JHDSM Family Variables, higher numbers indicate of increased familial concerns (i.e., worries about children/partner and conflict within the family). Scores range from 0 to 30. For JHDSM Physical Variables, higher numbers are indicative of increased physical concerns (i.e., side effects of treatment, eating, pain, and fatigue). Scores range from 0 to 40.
Table 10

*Means and Standard Deviations for Deviations for Jewish Hospital Distress Measure Spiritual Variables*

<table>
<thead>
<tr>
<th>Time</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1 Pre-admission</td>
<td>84</td>
<td>20.73 (8.47)</td>
</tr>
<tr>
<td>Time 2 Day before transplant</td>
<td>75</td>
<td>22.03 (8.65)</td>
</tr>
<tr>
<td>Time 3 1 weeks post-transplant</td>
<td>73</td>
<td>21.89 (7.95)</td>
</tr>
<tr>
<td>Time 4 2 weeks post-transplant</td>
<td>23</td>
<td>22.91 (9.32)</td>
</tr>
<tr>
<td>Time 5 3 weeks post-transplant</td>
<td>5</td>
<td>26.40 (5.37)</td>
</tr>
<tr>
<td>Time 6 Discharge</td>
<td>67</td>
<td>22.43 (9.66)</td>
</tr>
</tbody>
</table>

*Note.* Higher numbers are indicative of decreased spiritual concerns (i.e., sense of meaning and purpose, feeling cared for by a higher power, feeling supported by spiritual community). Scores range from 0 to 30.
Appendix A

Distress Thermometer

Removed due to Copyright.

This measure is available through National Cancer Comprehensive Network.

http://www.nccn.org/default.aspx
Appendix B

Hospital Anxiety and Depression Scale

Removed due to Copyright.

This measure is available through GL-Assessment.

http://www.gl-assessment.co.uk
Appendix C

Mastery Scale

Removed due to Copyright.

This measure is available through the American Sociological Association (ASA).

http://www.asanet.org/journals/permissions.cfm
Appendix D

Brief RCOPE

Removed due to Copyright.

This measure is available through *Religions* (Open Access Journal).

www.mdpi.com/journal/religions
Appendix E

Meaning in Life Scale

Removed due to Copyright.

This measure is available through The National Institute of Health.

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2168592/
### Appendix F

#### Jewish Hospital BMTU Distress Screening Measure

**Jewish Hospital BMTU**

Please circle the number that describes how much distress you are experiencing today:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Distress</td>
<td>Extreme Distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please circle the number that describes how much distress you have experienced in the past week:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Distress</td>
<td>Extreme Distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please circle the number that describes how much distress the following issues have caused you in the past week, including today:

- **Practical Issues:**
  - Concerns about daily care of children:
    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
    | No Problem | Extreme Problem |
  - Housing:
    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
    | No Problem | Extreme Problem |
  - Finances, bills, insurance:
    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
    | No Problem | Extreme Problem |
  - Work, concerns about job:
    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
    | No Problem | Extreme Problem |

- **Family Issues:**
  - Worries about children:
    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
    | No Problem | Extreme Problem |
  - Worries about partner, spouse, caregiver:
    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
    | No Problem | Extreme Problem |
  - Conflict in family:
    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
    | No Problem | Extreme Problem |

**Emotional Issues:**

- Sadness/Depression:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | None | Severe |
- Anxiety/Worry:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | None | Severe |
- Fear:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | None | Severe |
- Boredom:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | None | Severe |
- Loneliness:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | None | Severe |
- Homesickness:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | None | Severe |

**Spiritual Concerns:**

- I feel a sense of meaning and purpose:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | Not at all | Very Much |
- I feel cared for by a Higher Power:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | Not at all | Very Much |
- I feel support from my spiritual community:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | Not at all | Very Much |

**Physical Issues:**

- I am distressed by the side effects of treatment:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | Not at all | Extremely |
- Eating is a problem:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | Not at all | Severe |
- Pain is a problem:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | Not at all | Severe |
- Fatigue is a problem:
  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
  | Not at all | Severe |

**Additional problems or concerns:**

Administered by: ____________________________

Date: ____________________________
Appendix G

Informed Consent

A Statement of Informed Consent
1. Introduction

Before agreeing to participate in this study, entitled Trajectory of Distress for Bone Marrow Transplant Inpatients and Validation of Jewish Hospital BMTU Distress Screening Measure, it is important that you read and understand the following explanation of the proposed procedures. This statement describes the purpose, procedures, benefits, risks, discomforts and precautions of the study. It also describes the alternative procedures available to you and your right to withdraw from the study at any time. It is important for you to understand that no guarantee can be made as to the results. You have been chosen to participate in this study due to your status as a bone marrow transplant candidate who will be hospitalized at Jewish Hospital during the procedure.

2. Objectives

The purpose of this research study is to gain important information regarding the amount of distress that bone marrow transplant patients endure while they are hospitalized, and the specific times during which they experience the most distress. We believe it is important to treat the whole person, body, mind and spirit so we ask for your cooperation in accomplishing this by completing surveys once a week to assess their level of distress currently and over the past week. Once you have completed the surveys indicating their level of distress and the causes of their distress, the appropriate staff members of Jewish Hospital, such as the psychologist, social worker, chaplain, and medical support team can be notified and provide the necessary services.

3. Procedures

The following listed procedures will be used in this study:

Every bone marrow transplant patient on the unit is asked to complete a survey of distress on Monday of each week. The survey takes approximately 5-10 minutes to complete and is generally followed by a brief consult with the psychologist or psychology students. The surveys are then placed in the patients’ medical charts and used to provide the best treatment possible. By agreeing to participate in this research study, you will be allowing members of the psychology team at Jewish Hospital to make a copy of your completed surveys of distress and track your responses during the time you are hospitalized for your bone marrow transplant. You will also be asked to complete a brief demographics form upon admission to Jewish Hospital for your bone marrow transplant. You may dictate your responses to caregivers or staff members if you feel unable to complete the surveys, but others may not complete the surveys for you without you indicating your responses. Your name and identifying information will be removed from all of the surveys and the demographics form to ensure confidentiality and kept in a secured location for later data analysis. Psychology team members will also record any time you spend in isolation due to infection and if you begin any medications for depression, anxiety, or another
mood disorder. They may also review your medical chart for additional information related to your treatment.

4. Risks and Precautions
The following foreseeable risks and discomforts are involved in this study:

There are no foreseeable risks or discomforts involved in your participation in this study. Should any discomfort arise you should contact Dr. Lyn Sontag who is the psychologist on the bone marrow transplant unit at Jewish Hospital or any member of this research team.

5. Benefits
The following benefits may reasonably be expected from this study:

The information we collect from this study will be valuable in your treatment as well as treatment for future bone marrow transplant patients. By assessing your level of distress during hospitalization, and the causes of any discomfort you may feel, we will be better able to meet your needs. Through learning what types of services are needed and when our services can be of most help to meet your needs, we will be better able to meet your needs and the needs of future bone marrow transplant patients throughout their hospitalization. You may obtain results from this study after its completion which can be accomplished by contacting one of the research team members.

6. Alternative Procedures Available
The following alternative procedures are also available should you decide against participating in this study:

Should you choose to not participate in this study, you will still be asked to complete a weekly survey of distress during psychology rounds throughout your hospitalization to aid in your care and your concerns will be referred to the appropriate staff member. Your surveys will still be placed in your medical chart; however, no copies will be made of the surveys and your responses will not be tracked as part of this study. You will still be eligible for all of the services offered by Jewish Hospital, as well as the services provided the psychologist, social worker, and chaplain of this unit regardless of your participation in this study.

7. Right of Refusal
Participation in this study is voluntary. If you refuse to participate, there will be no penalty or loss of any benefit to which you are entitled. If you volunteer to participate in the study, you may withdraw from the study at anytime without penalty or loss of any benefit to which you are entitled.

8. Confidentiality
Your medical records will be treated as confidential. Only authorized personnel will have access to the records. It is possible that an authorized person from the Department of Health & Human Services (DHHS), Food & Drug Administration (FDA) or other federal agency will inspect the records. In all instances except FDA, in the case of a new drug investigation, the FDA does have the right to know your name and this may be revealed to the proper authorities from the FDA if requested to do so. Unauthorized persons will not be permitted to examine your records without your written consent.
9. **Availability of Information:**

   We very much appreciate your participation in this study and your willingness to aid us in providing the best services possible. Any questions that you may have concerning any aspect of this study or your rights as a participant in the study will be answered by:

   Dr. Lyn Sontag, Psy.D., ABPP (Principal Investigator)
   (513) 686-5237
   4777 East Galbraith Road
   Cincinnati, Ohio 45236
   lxsonntag@health-partners.org

   Ashley Arnott Barroquillo (Associate Investigator)
   (513) 686-5237
   4777 East Galbraith Road
   Cincinnati, Ohio 45236
   ash.arnott@gmail.com

   The Jewish Hospital of Cincinnati follows a policy of making all decisions concerning financial compensation of medical care for injuries occurring during or caused by participation in biomedical or behavioral research on a case-by-case basis. If you believe you have been injured as a result of any procedure of research, contact Stephen J. Goldberg, M.D., Chairman, The Jewish Hospital Institutional Review Board, (513) 686-5446.

**CONSENT**

I, ______________________________________________________, HAVE READ AND UNDERSTAND THE PRECEDING EXPLANATION, AND I CONSENT TO PARTICIPATE IN THE STUDY AS DESCRIBED ABOVE IN SECTION 2 CAPTIONED “OBJECTIVES”. I CONSENT TO THE PROCEDURES DESCRIBED IN SECTION 3 CAPTIONED “PROCEDURES”. I UNDERSTAND THAT I AM FREE TO WITHDRAW WITHOUT PENALTY OR LOSS OF BENEFIT FROM THIS INVESTIGATION AT ANY TIME. SHOULD I WISH TO WITHDRAW I HAVE BEEN ASSURED THAT STANDARD THERAPY FOR MY CONDITION WILL REMAIN AVAILABLE TO ME. I HAVE BEEN INFORMED OF THE PROBABALE CONSEQUENCES OF MY WITHDRAWL FROM THE STUDY.

SUBJECT: ______________________________________________________________________ DATE: ____________________

INVESTIGATOR: __________________________________________________________________ DATE: ____________________

WITNESS: ______________________________________________________________________ DATE: ____________________
Appendix H

Demographics Form

ID #: ____________________________
Date of birth: ______________________
Male or Female (circle one)
Race/Ethnicity:
   a. White/Non-Hispanic
   b. African American
   c. Hispanic
   d. Asian/Pacific Islander
   e. American Indian/Alaska Native
   f. Other __________

Education Level:
   a. Less than high school diploma
   b. High school diploma/GED
   c. Associate degree
   d. Bachelor’s degree
   e. Some graduate school
   f. Graduate degree
   f. Other __________

Marital Status:
   a. Single
   b. Married
   c. Life partner
   d. Separated
   e. Divorced
   f. Widowed
   g. Other __________

Total Household Annual Income:
   a. Less than $9,999
   b. $10,000 to $19,999
   c. $20,000 to $29,999
   d. $30,000 to $39,999
   e. $40,000 to $49,999
   f. $50,000 to $59,999
   g. $60,000 to $69,000
   h. $70,000 to $79,999
   i. $80,000 to $89,999
   j. $90,000 to $99,000
   k. $100,000 or above
Appendix I

Jewish Hospital IRB Approval Document

THE JEWISH HOSPITAL OF CINCINNATI
INSTITUTIONAL REVIEW BOARD
4777 EAST GALBRAITH ROAD
CINCINNATI, OHIO 45236
(513) 686-5446/ FAX (513) 686-5443

DATE: June 8, 2010

TO: Lyn Sontag, M.D.

FROM: Stephen Goldberg, MD
Chairperson, Jewish Hospital Institutional Review Board
FDA #: FWA00002824

RE: Protocol # 10-08

The Jewish Hospital Institutional Review Board reviewed your protocol on 5/18/10, entitled “Trajectory of Distress for Bone Marrow Transplant Inpatients and Validation of Jewish Hospital BMTU Distress Screening Measure”. The following action was taken:

X Protocol/Consent Form Approved; Protocol Activated 6/5/10
Protocol/Consent Form Approved for Continuation for one year
Progress Report Approved/Protocol Closed
Notification Received and Noted

Sincerely,

[Signature]
Stephen J. Goldberg, M.D.
Chairman, Institutional Review Committee

X Stephen Goldberg, M.D.    Chris Heck
X Miriam Warshauer           X Kenneth Washington
Waqas Ahmed, M.D.            X Fr. Dale Peterka
Appendix J

Xavier University IRB Approval Document

October 18, 2013

Ashley Barroquillo
405 A Brigadier Lane
Fort Wright, KY 41011

Re: Protocol #1299-11, Trajectory of Distress of Bone Marrow Transplant Inpatients and Validation of Jewish Hospital BMTU Distress Screening Measure

Dear Ms. Barroquillo:

The IRB has reviewed the materials regarding your study, referenced above, and has determined that it meets the criteria for the Exempt from Review category under Federal Regulation 45CFR46. Your protocol is approved as exempt research, and therefore requires no further oversight by the IRB. We appreciate your thorough treatment of the issues raised.

If you wish to modify your study, including the addition of data collection sites, it will be necessary to obtain IRB approval prior to implementing the modification. If any adverse events occur, please notify the IRB immediately.

Please contact our office if you have any questions. We wish you success with your project!

Sincerely,

[Signature]

Morell E. Mullins, Jr., Ph.D.
Chair, Institutional Review Board
Xavier University

MEM/sb

C: Renee Zucchero, Advisor
Appendix K

Weekly Progress Note

Patient ID Number:
Date of Admission: 
Date of Discharge: 
Medical Issues / Complications (please indicate the date these occurred):

Admission Measure (check when completed) ______

Week 1 Measure ______  
Patient in isolation? Yes or No (circle one)  
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 2 Measure ______  
Patient in isolation? Yes or No (circle one)  
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 3 Measure ______  
Patient in isolation? Yes or No (circle one)  
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 4 Measure ______  
Patient in isolation? Yes or No (circle one)  
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 5 Measure ______  
Patient in isolation? Yes or No (circle one)  
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 6 Measure ______  
Patient in isolation? Yes or No (circle one)  
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)

Week 7 Measure ______  
Patient in isolation? Yes or No (circle one)  
Patient began taking medication for depression, anxiety, or another mood disorder? Yes or No (circle one)
Appendix L

Permission for use of Distress Thermometer

National Comprehensive Cancer Network*

April 16, 2010
Lyn Sontag, Psy.D.
Jewish Hospital
4777 East Galbraith Road
Cincinnati, OH 45236

Dear Dr. Sontag:

On behalf of the National Comprehensive Cancer Network ("NCCN") I am writing to grant you limited one time permission to reproduce the Distress Thermometer Screening Tool FIGURE (DIS-A) from the NCCN 1.2010 Distress Management Guidelines for use with your patients. Permission is granted solely for the purposes described herein which you represent and warrant to be for non-promotional educational use only. The following qualifications also apply to the permission granted by this letter:

3. You agree to include a citation giving full credit to the NCCN for these Guidelines as follows:


4. Permission is for one time use only and expires after one year.

3. You must initial this letter to denote your acceptance of the terms/stipulations in this letter, and fax it back to NCCN at 215-690-0283 to the attention of Nicole Fair.

4. You agree that you will not translate, change, adapt, delete, extract portions, or modify the content of the NCCN 1.2010 Distress Management Guidelines.

5. Permission is for reproduction of the Guidelines in print media only. No Electronic Rights (including CD-ROM and Internet) are granted. Reproduction of the Guidelines into any other medium, including but not limited to electronic media, is explicitly prohibited. You further agree that any reproduction of the Guidelines will include NCCN’s URL address www.nccn.org, to link to the most updated version of the NCCN Distress Management Guideline.

6. Permission is granted for reproduction in the English language only.

7. You agree that the following statements shall be conspicuously included in all guideline reproductions:

   “These Guidelines are a work in progress that will be refined as often as new significant data becomes available.”

   “The NCCN Guidelines are a statement of consensus of its authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult any NCCN guideline is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient’s care or treatment. The National Comprehensive Cancer Network makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.”
Appendix M

Permission for use of Hospital Anxiety and Depression Scale

Granada Learning

INVOICE TO:
Account No 124379
Lyn Sontag PsyD
Clinical Psychologist
Jewish Hospital BMTC
4777E Galbraith Road
CINCINNATI
Ohio
45238
United States

DELIVER TO:
Account No 124379
Lyn Sontag PsyD
Clinical Psychologist
Jewish Hospital BMTC
4777E Galbraith Road
CINCINNATI
Ohio
45238
United States

Our Order Number 822804
Order Date 13 January 2011

Order Processed By: egiles
Customer Order Number: Sontag130111

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Total: £20.00

Discount: £0.00
VAT: £0.00

Final Price: £20.00

Payment Accepted via Cheque, Credit Card or BACS.
Cheques made payable to Granada Learning Ltd
BACS: Barclays Bank Plc
A/C No: 10435317
Sort Code: 20-78-98
Bank Swift Code: BARCGB22
(for international use)

Please send payment and all payment enquiries to:
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Tel: 01793 516 347 Fax: 01793 515 515

All other enquiries to:
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Customer Services
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Techno Trading Estate
Swindon Wilts UK SN2 8EZ
Tel: 01793 502 1937 Fax: 01793 501 5358

This sale is subject to Granada Learning Standard Terms and Conditions.
8. You acknowledge that the NCCN is sole owner of the Guidelines, and any derivative works created from the Guidelines. You further acknowledge that the NCCN is the owner of the name “National Comprehensive Cancer Network, Inc.,” and “the NCCNs” and any derivatives thereof (the “Marks”). You agree that you shall not use the Marks in any manner or for any purpose other than to acknowledge ownership of the Guidelines by the NCCN as described in this letter. Your use of the Marks and/or Guidelines for the purposes described herein in no way constitutes an endorsement of your works or opinions by the NCCN. You acknowledge that use of the Marks and reprinting of the Guidelines pursuant to the permission granted hereunder shall not create in your favor any right, title, or interest in or to the Marks and/or the Guidelines. The permission granted hereunder is for a one-time use of the Marks and/or Guidelines. You agree that each use of the Marks and/or the Guidelines by you, beyond or in addition to that described herein, shall require written approval by the NCCN.

9. Your use of the Marks and/or Guidelines as described herein shall signify your acceptance of the terms and conditions of this letter. The NCCN reserves the right to at any time revoke the permission granted hereunder if, in its discretion, the NCCN determines that you have violated or are in violation of the terms of this letter of permission.

Thank you for your interest in the work of the NCCN.

Sincerely,

[Signature]

Lynn Cherrin, MS
CE Program Manager
NCCN
Sontag/4-16-2010
Appendix M

Permission for use of Hospital Anxiety and Depression Scale

Granada Learning

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This is a Pro Forma Invoice

Total: £90.00

Payment: Accepted via Cheque Credit Card or BACS.
Cheques made payable to Granada Learning Ltd
BACS: Barclays Bank Plc A/c No: 10435817 Sort Code: 20.78.86
Bank Swift Code: BARCGB21 (for International use)

Please send payment and all payment enquiries to:
Granada Learning Distribution Service Credit Control
Unit 28 - Bramble Road
Techno Trading Estate
Swindon Wiltshire SN2 8EZ
Tel: 01793 516 347 Fax: 0845 601 5557

All other enquiries to:
Granada Learning Ltd Customer Services
Unit 28 - Bramble Road
Techno Trading Estate
Swindon Wiltshire SN2 8EZ
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Appendix N

Permission for use of Mastery Scale

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References


Appendix O

Permission for use of Brief RCOPE

from Kenneth I Pargament <kpargam@bgsu.edu>
to Ashley Barroquillo <ash.amott@gmail.com>
date Wed, Sep 8, 2010 at 7:53 AM
subject RE: Brief RCOPE measure
mailed-by bgsu.edu

Dear Ashley:

You have my permission to use the Brief RCOPE. I’ve attached a manual. Let me know if you have any questions. Please keep me posted on your findings.

Best regards,
Ken Pargament
Appendix P

Permission for use of Meaning in Life Scale

from Barb Andersen <andersen.1@osu.edu>
to Ashley Barroquillo <ash.arnott@gmail.com>
date Tue, Sep 7, 2010 at 9:25 AM hide details 9/7/10
subject Re: Meaning in Life Scale
mailed-by osu.edu

No permission needed. Public domain.
Appendix Q

Summary

*Title:* Trajectory of Distress for Bone Marrow Transplant Inpatients and Validation of Jewish Hospital BMTU Distress Screening Measure

*Problem.* High levels of distress are common among cancer patients (Hoffman, Zevon, D’Arrigo, & Cecchini, 2004; Jacobsen et al., 2005; Trask et al., 2002). As many as one third to over one half of cancer patients report significant distress (Carlson et al., 2004; Lee et al., 2005; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001), although fewer than 10% are referred for professional psychosocial care (Carlson & Bultz, 2003). Unfortunately, distress is often not recognized by oncology professionals decreasing the likelihood of psychosocial intervention (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Sollner et al., 2001). Leading institutions such as the National Comprehensive Cancer Network (NCCN) recognize psychological distress as a significant concern for individuals with cancer and strongly recommend routine assessment of distress (Holland et al., 2010). There were three important aims for the current study. The first was to establish a trajectory of distress for bone marrow transplant (BMT) inpatients throughout hospitalization. The second was to determine variables that contribute to patient distress. The third was to validate a new screening measure for distress specifically developed for use with bone marrow transplant inpatients.

Additional measures may be useful in further identifying variables that increase patient distress. For this reason, personal control, sense of meaning in life, and religious coping styles were also assessed in the current study. Unique to this study, the Meaning in Life Scale (MiLS) examined change in patient perspective of meaning during the BMT process, as well as the interaction with religious coping and change over time. This study also sought to establish a trajectory of distress
as in preceding studies (e.g., Fife et al., 2000; Molassiotis et al., 1996), while assessing a unique combination of variables contributing to distress. Additionally, BMT patient distress levels were assessed more frequently than in past studies (e.g., Ho, Horne, & Szer 2002; Sherman et al., 2009; Wells et al., 2009) to gain a more detailed depiction of a trajectory of distress during transplantation. The results of this study will offer valuable information to the Bone and Marrow Transplant Program at Jewish Hospital and aid in patient care.

Method. This study seized the crucial opportunity presented during hospitalization to assess and assist BMT patients with psychological distress. Eighty-five bone marrow transplant inpatients of Jewish Hospital participated from June 2010 through February 2013. Participants were receiving their first autologous or allogeneic BMT. Participants completed a demographic questionnaire, Distress Thermometer (DT), Jewish Hospital Distress Screening Measure (JHDSM), Mastery Scale, Hospital Anxiety and Depression Scale (HADS), Brief RCOPE, and MiLS at the time of their initial evaluation, which constituted a baseline measurement. Participants completed the DT, JHDSM, Mastery Scale, Brief RCOPE, and MiLS the day prior to bone marrow transplantation. Post-transplant, participants completed a specified set of measures each Monday during psychology rounds until they were discharged from the hospital.

Findings. The researcher hypothesized that patient distress levels would be highest the day prior to BMT and would decrease throughout hospitalization. This hypothesis was not supported as no point in the trajectory could be identified as the highest point of distress. However, the point of lowest distress, as assessed by JHDSM1, was at the time of discharge. As hypothesized, emotional, practical, family, physical, perceived level of personal control, meaning of life event, religious coping style, and perceived level of social support significantly contributed to patient distress throughout hospitalization. Interestingly, spiritual concerns were not predictive of
distress (using JHDSMI as the dependent variable) except one week post-transplant when spiritual concerns were negatively correlated with patient distress. Patient demographic variables also did not influence patient distress levels nor did type of transplant received (i.e., allogeneic versus autologous). Using the DT, the JHDSM was validated as a screening measure for use with bone marrow transplant inpatients.

Implications. Participants did not endorse a high degree of psychological distress throughout hospitalization for BMT, which likely accounts for the decreased variability in distress during the study. Low levels of distress may be attributable to the use of different measures of distress than in previous research, a greater level of education regarding what to expect throughout the process of bone marrow transplant provided at Jewish Hospital, varying hospital policies (e.g., time spent in isolation), and the fact that Jewish Hospital employs a psychologist, social worker and chaplain as resources for bone marrow transplant patients. Important to note, patients who chose to participate in the study likely experienced fewer complications throughout hospitalization than those who either declined to participate or terminated their participation.

Unique to this study, the MiLS was used to examine change in patient perspective of meaning during the BMT process. The results were compelling in establishing the importance of the meaning of the event (i.e., cancer diagnosis and treatment) as a contributor to patient distress. The ability to find meaning in life, maintain a positive religious coping style, a perception of personal control, and the support of others were identified as potential protective factors for patients undergoing BMT. Specifically assessing these factors prior to admission to the hospital can provide clinicians with a more comprehensive understanding of patient strengths and limitations and help to identify patients who may benefit from additional support throughout BMT.