THE 6\textsuperscript{TH} VITAL SIGN IN MEDICINE: EVALUATION OF A
COMPREHENSIVE MODEL OF DISTRESS IN CANCER CARE

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Abstract

by

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Cancer is the second leading cause of mortality in America and has a profound impact upon individuals, families, health care providers, and society at large. A substantial minority of cancer patients experience clinically significant symptoms of psychological distress, which can be associated with a wide range of negative health outcomes. Currently available screening measures narrowly define distress, are relatively primitive tools and their relationship to patient behavior is largely unknown. The current study sought to evaluate the psychometric properties and clinical utility of Distress Screening System (DSS), a comprehensive measure developed to address these limitations. There were 492 individuals diagnosed with cancer assessed in the current study through mail-out questionnaires and follow-up phone interviews. The majority were female (71.3%), married (59.6%) and Caucasian (68.6%) or African American (20.7%), with a mean age of 61.41 years ($SD = 12.92$). Preliminary and exploratory
factor analysis revealed the DSS to possess appropriate internal and concurrent validity, and to be sufficiently unidimensional to proceed with further examination. Item response analysis revealed moderate overall model fit, with the majority of items performing well with adequate levels of discrimination and difficulty across the distress continuum. The DSS was most accurate in assessing moderate to high levels of distress. Examination of clinical utility revealed no significant advantage for the DSS in predicting quality of life or referral preference. The DSS appears to be a psychometrically valid measure of distress and provides the basis for a broader conceptualization of this construct. The majority of items performed well within a unidimensional item response framework and may therefore be suitable to utilize within a computerized assessment format. Despite these results, the DSS did not demonstrate a significant advantage in the prediction of participants’ quality of life or referral preference. The current study provides a foundation for future work examining the conceptualization of distress and development of screening tools within an advanced psychometric framework and computerized administration. Advances in empirical measurement and clinical assessment are vital in addressing the ongoing challenge of providing nationwide comprehensive cancer care.
I dedicate this work to my wife, Jennifer, and my family and friends for their unwavering support and encouragement over the course of the past five years.
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CHAPTER 1:
INTRODUCTION

1.1 Psychological Distress in Cancer

Cancer is the second leading cause of mortality in America (ACS, 2010). Recent estimates indicate that approximately one in two men and one in three women will be diagnosed with some form of cancer during their lifetime (ACS). According to the American Cancer Society, the cost of cancer totaled greater than $219 billion in 2007 including health care costs and lost productivity due to illness or premature death (ACS). Cancer is a general term used to identify a disease state in which abnormal cells continue to grow out of control and potentially invade other tissues and organs. Cancer cells can spread through the blood or lymph systems to other parts of the body, a process referred to as metastasis. Cancer is difficult to treat due partially to the fact there are over 100 different types of cancer; thus requiring a combination of treatment modalities and the formulation of individualized plans for those diagnosed (ACS). Advances in medical science, along with increased public awareness and early detection of cancers, have resulted in many more individuals surviving cancer (Alfano & Rowland, 2006; Earle, 2006; Hewitt, Greenfield, & Stovall, 2005). Despite increased rates of survival, the
diagnosis of cancer can constitute a traumatic, fearful, and distressing event. This can prompt consideration of one’s own mortality and the reevaluation of life-goals and interpersonal relationships.

The detection, treatment, and long term management of cancer has been associated with significant psychological distress (Zabora, BrintzenhoefSzoc, Curbow, Hooker, & Piantadosi, 2001), with depression and anxiety the most frequently documented disorders in adult cancer patients (Massie, 2004; Newport & Nemeroff, 1998; Stark & House, 2000). Psychological distress can result from the need to cope with many types of stressors, including not only physical symptoms and side-effects, but also employment and financial problems, management of frequent medical visits, and difficulties maintaining family commitments and interpersonal relationships. Due to the multitude of possible stressors, it is estimated that between 25% to 45% of patients experience clinically significant symptoms of psychological distress at some stage of the cancer disease trajectory, with higher rates associated with more advanced disease status, pain and higher levels of physical disability (Carlson & Bultz, 2003b; Derogatis, et al., 1983; Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Kathol, Mutgi, Williams, Clamon, & Noyes, 1990; Potash & Breitbart, 2002; Sellick & Edwardson, 2007; Zabora, et al.). In acknowledgement of the profound impact cancer can have upon individuals, families, health care providers and society at large, the evaluation of a comprehensive model of distress, along with the development and preliminary validation of the proposed Distress Screening System (DSS), will take place within an oncology setting.
A number of studies have sought to accurately establish the prevalence of distress, most frequently operationalized as depression and anxiety, associated with the cancer experience. In one of the earliest and most frequently cited assessments of psychological distress in cancer patients, Derogatis and colleagues (1983) reported that 47% of a heterogeneous sample of cancer patients met criteria for an Axis I disorder. In a more recent study of 4496 mixed cancer patients, Zabora and colleagues (2001) reported that 24.1% and 18.7% of patients endorsed clinically significant symptoms of anxiety and depression, respectively. In further studies, Dugan, Passik and Theobold (1996) reported that 35% of a heterogeneous sample of 1109 ambulatory cancer patients endorsed clinically significant depressive symptoms. Similar rates of distress have been associated with studies of specific cancer diagnoses. For example, in a systematic review of the literature, Arden-Close and colleagues (2008) reported that studies that possessed high quality methodology reported rates of depression to be between 21% and 25% in patients diagnosed with ovarian cancer. Finally, Mitchell (2007) conducted a meta-analysis of studies that assessed psychological distress in cancer patients using brief screening measures. In total, over six thousand patients were assessed across thirty-eight studies. Clinically significant depression was reported by 18% of patients, anxiety by 38%, and general distress by 39% of this sample.

In response to these prevalence statistics, the National Institutes of Health (NIH; Adler & Page, 2007) and the Institutes of Medicine (IOM; Hewitt, et al., 2005) have emphasized the importance for health-care providers to address the psychological needs of cancer patients, both through the effective detection of distress and the provision of
appropriate support services. Importantly, the failure to identify patients in need of support jeopardizes the provision of effective care, increases care-related costs, and can negatively impact a patient’s quality of life and ability to manage their disease. Proponents of effective distress screening and treatment have sought to have distress identified as the sixth vital sign in medical care (Bultz & Carlson, 2005, 2006). This recommendation has already been adopted in Canadian healthcare practice (CAPC, 2008) and is predicted to both normalize patients’ report of distress and ensure that it is routinely assessed by health care providers.

The current proposal will seek to evaluate a more comprehensive and sophisticated model of distress than currently exists. Modern psychometrics will enable a theoretically grounded, highly-sensitive and sophisticated screening measure for psychological distress to be examined within the context of this comprehensive model. In addition, the current study will extend research in distress screening through the evaluation of the ability of the DSS and existing screening measures to predict quality of life and patients’ likelihood of requesting a support service referral. To the knowledge of the author, the proposed conceptualization of distress, employment of advanced psychometrics, and prediction of patient planned behavior, has not previously been undertaken. The results of the current study will seek to significantly shift the conceptualization, measurement and screening of distress in cancer and enhance the provision of comprehensive care in America.
1.2 Psychological Distress and Health Outcomes

Psychological distress in cancer has been associated with a wide range of negative health outcomes, including impaired quality of life, difficulties maintaining personal and professional roles and interpersonal relationships, as well as impaired immunoregulation (Glaser, 2005; Kiecolt-Glaser, Robles, Heffner, Loving, & Glaser, 2002; Maier & Watkins, 2003) and disease recovery. Patients’ quality of life (QOL) incorporates their appraisal of both the effects of a clinical diagnosis, as well as treatment side-effects and can provide a global indication of well-being, which can be important information in optimizing medical treatment (Guyatt, Feeny, & Patrick, 1993; Nanda & Andresen, 1998; Oldridge, 1996; Soni & Cella, 2002; Velikova, et al., 2004). Individuals who report symptoms of distress also consistently report greater impairment in those domains that are most frequently assessed by quality of life measures; including social and family well-being, emotional well-being, functional well-being and physical well-being (Hopko, et al., 2008; Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000). For example, Frick, Tyroller and Panzer (2007) reported a significant correlation between distress, as measured by the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and overall quality of life in patients undergoing radiation therapy. A similar significant finding was reported by Arden-Close and colleagues (2008) in a broad meta-analysis concerning the relationship between distress and quality of life in ovarian cancer patients. The authors identified eighteen studies that were sufficiently methodologically robust to include, reporting that poorer quality of life was significantly and consistently associated with higher rates of reported distress. It is important to note that these studies
did not assess distress and quality of life over time and therefore no causal arguments could be established.

Tagay and colleagues (2006), in an investigation of thyroid cancer patients’ psychological well-being, reported that participants’ distress was a significant predictor of their quality of life. Similar findings were reported in studies of advanced stage cancer patients (Mystakidou, et al., 2005; Smith, Gomm, & Dickens, 2003), with endorsed symptoms of anxiety and depression identified as important factors in predicting participants’ overall quality of life. Further, Schreier and Williams (2004) explored the role of anxiety in predicting patients’ quality of life at the start of chemotherapy treatment as well as at a post-treatment follow-up appointment one year later. Importantly, this longitudinal study found that patients who endorsed higher levels of anxiety at the beginning of treatment were more likely to report impaired quality of life both at the beginning of treatment and at the follow-up appointment. Finally, Redeker, Lev and Ruggiero (2000) examined the contribution of a range of psychosocial variables in predicting quality of life in a sample of mixed diagnoses cancer patients. The authors reported a significant negative correlation between distress and patients’ quality of life with symptoms of depression explaining the largest portion of variance in quality of life. Empirical research has therefore demonstrated a consistent association between symptoms of distress associated with the cancer experience and impaired quality of life across individual domains and globally.

Further research has established an association between psychological distress and a range of negative outcomes, including reduced medical compliance (Kennard, et
al., 2004), prolonged hospitalization (Prieto, et al., 2002), lower levels of satisfaction with care (Bui, Ostir, Kuo, Freeman, & Goodwin, 2005; Von Essen, Larsson, Oberg, & Sjoden, 2002) and greater dropout rates in clinical trials (Kelly, Ghazi, & Caldwell, 2002). Failing to address psychological distress in a cancer setting has also been shown to increase the likelihood that patients will seek care at community and emergency services (Carlson & Bultz, 2003b) and require more extended care in the future (Ashbury, Findlay, Reynolds, & McKerracher, 1998). Importantly, once detected, treatments for psychological distress associated with cancer has demonstrated consistent efficacy (Andersen, et al., 2007; Osborn, Demoncada, & Feuerstein, 2006), as well as cost-effectiveness in reducing the negative economic impact of untreated psychological disorders (Carlson & Bultz, 2003a).

1.3 Psychological Distress and Immunoregulation

An extensive body of literature now exists that has investigated the possible impact that psychological distress may have on a patients’ immune system and recovery from disease, particularly in regard to cancer. The proposal that psychological states may be associated with the functioning of the immune system and outcome of human disease is not new; in AD 200 Galen hypothesized that melancholic women were at a greater risk of developing certain disease states (Leonard, 1987). In the past two decades however, a broad range of scientific disciplines have sought to establish an empirical foundation for this possible association and to elucidate the mechanisms by which the central nervous, endocrine, and immune systems may interact to influence behavior and the course of disease (Glaser, 2005; Kiecolt-Glaser, et al., 2002; Maier & Watkins, 2003). Research in
this domain has sought evidence in regard to a range of disease and non-disease states, including cancer, and has thus far provided evidence for the involvement of both broad system regulation, such as the hypothalamic-pituitary-adrenal axis and cortisol regulation (Antoni, 2003; Reiche, Nunes, & Morimoto, 2004; Smith & Vale, 2006), as well as the intricate cellular immunoregulation of cytokine and natural killer (NK) cell concentrations within the immune system (Kiecolt-Glaser, et al., 2002).

In cancer, dysregulated cortisol levels have been associated with immunosuppression (Sephton, et al., 2009), depression (Giese-Davis, et al., 2006) and diagnostic uncertainty and worry (Lang, Berbaum, & Lutgendorf, 2009). Further research has suggested that a number of cytokines, most notably the proinflammatory cytokines, Interleukin-1 (IL-1), Interleukin-6 (IL-6) and tumor necrosis factor (TNF), along with NK cells, are consistently associated with psychological distress and impaired well-being (O'Brien, Scott, & Dinan, 2004). NK cells represent an important line of defense against infection and surveillance of tumor cells (Herberman & Ortaldo, 1981; Welsh, 1986; Whiteside & Herberman, 1989) and can be regulated through neuroendocrine pathways (Levy, Herberman, Lippman, & d'Angelo, 1987) and cytokine levels (Herberman & Ortaldo, 1981). Further, preliminary associations have also been established between NK cell cytotoxicity and disease development and progression, possibly through these cells’ role in the repair of damaged DNA and apoptosis (Kiecolt-Glaser, et al., 2002).

Cytokines and NK cells therefore appear to represent two potential mechanisms by which psychological distress may influence immunoregulation and possibly the course of disease over time.
Whereas the majority of empirical investigation has focused upon the associations between states of distress and immunoregulation, recent studies have also sought to establish this relationship in regard to positive factors and the enhancement of immunoregulation (Antoni, et al., 2006). For example, Lutgendorf et al., (2005) reported a significant association between social support and changes in the cellular immune response in women diagnosed with ovarian cancer. Importantly, evidence such as this has provided a foundation for investigation into the role of psychological interventions in not only reducing psychological distress, but also improving immunoregulation (Kiecolt-Glaser & Glaser, 1999; McGregor & Antoni, 2009).

1.4 Screening for Psychological Distress in Cancer

Despite the importance of providing comprehensive care that addresses patients’ psychological well-being, a number of barriers exist in the provision of support services. Whereas recent studies estimate that between 25% and 45% of cancer patients experience clinically significant distress, less than 10% of patients are seen by a mental health professional (Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005). In a large-scale assessment of the delivery of psychosocial services to cancer patients and their families, the IOM and NIH concluded that patients’ psychosocial needs were not being appropriately met by health care providers (Adler & Page, 2007; Hewitt, et al., 2005). Research has also established that physicians may not be able to reliably detect cancer patients with psychological distress and make appropriate referrals to support services (Fallowfield, et al., 2001; Newell, Sanson-Fisher, Girgis, & Bonaventura, 1998; Passik, et al., 1998; Sollner, et al., 2001). Physicians are often restricted in the time spent
with patients, may possess limited training in detecting and assessing psychological
distress (Merckaert, et al., 2008; Ryan, et al., 2005; Stewart, 1995), and may not
acknowledge the importance of psychological care (Levinson & Roter, 1995). Further,
patients may be unwilling to speak to health care providers directly about psychological
or emotional distress (Maguire, 1985; Okuyama, et al., 2008; Valente, Saunders, &
Cohen, 1994). Research has provided evidence that psychological disorders such as
depression and anxiety are important and treatable sources of distress often associated
with the cancer experience and thus emphasizes the need for routine screening of patients
(NCCN, 2008).

The need to detect and treat psychological distress associated with cancer has
resulted in the development and use of brief screening measures that patients can
complete at the point of care. However, despite the widespread use of such measures,
including the HADS (Zigmond & Snaith, 1983) and the Distress Thermometer (DT;
Roth, et al., 1998), the clinical utility and validity of such brief measures has been
questioned (Mitchell, 2007). Further, such measures predominantly conceptualize distress
as symptoms of depression and anxiety and may fail to acknowledge the complex and
multifaceted nature of patient distress. This narrow definition may limit the predictive
capacity of brief measures, as well as providing a limited degree of information to health
care providers and support service staff.

The HADS is a 14-item self-report measure that is designed specifically to assess
depression and anxiety in persons with physical illness and has demonstrated moderate to
good sensitivity and specificity in an oncology setting. For example, Walker and
colleagues (2007) evaluated the performance of the HADS in detecting major depressive disorder in a sample of 361 cancer patients with mixed diagnoses. Receiver Operating Characteristic (ROC) curve analysis revealed moderate to good sensitivity (.87) and specificity (.85) in detecting patients with major depressive disorder. In contrast, Love and colleagues (2004) evaluated the ability of the HADS to detect depression in women with late stage breast cancer. This measure was compared to a psychiatric interview in its ability to predict DSM-IV major and subsyndromal depression. The HADS demonstrated excellent specificity (.97) but very poor sensitivity (.16). In addition, Love and colleagues reported the HADS to be limited in its predictive capacity in early stage breast cancer patients, while Hall established lower rates of sensitivity for detected depression (.37) and anxiety (.72) in this same population (Hall, A'Hern, & Fallowfield, 1999). These results were obtained after lowering the threshold below the recommended cutoff, thus diminishing the specificity of the measure. Based on this study, the authors questioned the clinical utility of the HADS in screening for distress in this population. Lloyd-Williams and colleagues (2001) examined the validity of the HADS in screening for depression and anxiety in patients diagnosed with metastatic cancer. The authors reported a lower rate of sensitivity (.68) and specificity (.67) than in general cancer populations and also recommended that the HADS be used only in combination with other measure for screening in a palliative care setting. Translated versions of the HADS have demonstrated adequate reliability and validity in assessing depression and anxiety in cancer in India (Thomas, et al., 2005), Slovenia (Miklavcic, Snoj, Mlakar, & Pregelj, 2008) and Greece (Mystakidou, et al., 2004), amongst others. Despite its frequent use in
medical settings, the validity of this measure has been questioned in assessing distress in a number of medical populations, including newly diagnosed breast cancer patients (Hall, et al., 1999) and those in palliative care (Lloyd-Williams, et al.). In addition, the debate continues in regard to whether this measure consists of two or three distinct factors (Johnston, Pollard, & Hennessey, 2000; Rodgers, Martin, Morse, Kendell, & Verrill, 2005; Smith, et al., 2002).

In order to maximize clinical efficiency even further, ultra-brief screening measures have been developed, including the Distress Thermometer (Roth, et al., 1998) and the National Comprehensive Cancer Network (NCCN) Distress Measure (DMSM; NCCN, 2007). The Distress Thermometer is a brief, single-item visual analog scale that has been used in a number of clinical settings and which provides patients with a ten point scale on which to indicate their current level of distress. Research has established the DT to possess moderate to good sensitivity and specificity in a number of cancer populations, including, for example, newly diagnosed women with breast cancer (Hegel, et al., 2008) and ambulatory mixed diagnoses cancer patients (Jacobsen, et al., 2005). Whereas the DT can be completed rapidly at the point of care, it is only able to provide limited information, both in regard to sensitivity and specificity in detecting distress and the degree of information gathered for health care providers (Mitchell, 2007). This measure can assist health professionals in determining whether a number of follow-up questions may be appropriate in assessing a patients’ distress; however, in a time-limited clinical setting it is unable to assist in triage to appropriate support services, or provide health professionals with information regarding the source of distress. Further, possible
moderators of distress, both in the form of patient strengths or stressors, are not evaluated in the prediction of distress, nor does the DT identify whether a patient is interested in accessing services.

In response to the limited information provided by the DT, the NCCN recently published the DMSM, an expanded distress scale that includes the DT in addition to a list of physical symptoms and possible stressors that a patient will either confirm or deny (NCCN, 2007). Empirical research on this measure is sparse due to its recent development. In a sample of 68 mixed site cancer patients Hoffman and colleagues (2004) reported the DMSM to possess a moderate ability to detect distress, as identified by the Brief Symptom Inventory. However, ROC curve analysis did not identify a single cutoff score that maximized sensitivity and specificity, thus limiting its general utility. In a narrative evaluation of the DMSM, Dabrowski and colleagues (2007) reported this measure to be effective in promoting a greater level of communication between medical staff and breast cancer patients, along with assisting in the triage and prioritization of patients’ clinical and psychosocial needs. While the DMSM maintains a degree of brevity and does indeed provide greater detail regarding a patients’ psychological status, a number of disadvantages remain. The information gathered by this measure is neither utilized in the prediction of distress, nor in the decision about whether follow-up attention is indicated. Further, this measure is most frequently utilized in a paper and pencil format and thus patients’ responses are not flagged or identified to alert health professionals. Thus, the DMSM requires visual assessment of the symptom and stressor list by a health professional prior to the physician visit. Whereas it has indeed been shown to be
advantageous to approach patients with specific information regarding their distress 
(Carlson & Bultz, 2003b), in a clinical setting such tasks can quickly become 
unmanageable and in turn ignored. Further, the DMSM fails to recognize and assess the 
possible influence of moderators that may buffer the level of psychological distress, 
including positive coping mechanisms and social support.

In more recent work, Beuwens and colleagues (2008) sought to improve the 
utility of the DT through development and validation of the Distress Barometer (DB) for 
cancer patients. The authors utilized the DT, along with the Colored Complaint Scale 
(CDS), a color-coded system to alert health professionals to the degree to which stressors 
were endorsed by patients, and the Wish-Needs-Questions, three questions to determine 
patients desire to speak to a health professional. In predicting distress, the authors utilized 
information from the DT and CDS and established a greater level of sensitivity and 
specificity than previously found with the DT alone. These gains were modest however, 
with the new DB establishing a sensitivity of .79 and specificity of .81. In methodological 
terms, Beuwens et al. improved the sophistication by which a brief screening measure 
could detect distress through incorporating information regarding a patient’s global 
distress, as well the degree to which they endorse sources of distress.

An alternative extension of the DT has also been put forward by Mitchell and 
colleagues (2009) who have developed the Emotion Thermometer. This measure expands 
the use of the 0-10 visual analogue scales to include not only distress, but also anger, 
anxiety and depression, as well measures of distress burden and duration. A further 0-10 
scale is used to assess a patient’s need for help. Preliminary analysis of this measure
revealed greater diagnostic accuracy than the DT alone, with moderate to good levels of sensitivity and specificity achieved in relation to the HADS scale and a DSM-IV major depression diagnosis. Importantly however, neither the Emotion Thermometer nor the Distress Barometer acknowledge the potential role of patient-based factors such as coping efficacy and social support in predicting distress and the need for supportive services.

In a comprehensive review of brief measures used to detect cancer-related distress, Mitchell (2007) established pooled rates of sensitivity (correct identification of positive cases), specificity (correct identification of negative cases), positive predictive value (PPV; correct positive identifications / all positive identifications) and negative predictive value (NPV; correct negative identifications / all negative identifications) for distress across thirty-eight empirical studies. In all, 6,414 patients were screened for distress in these studies, predominantly with the single item Distress Thermometer, and the predictive values were compared with that of accepted measures of depression and anxiety. The authors reported that across all studies, the capacity to detect depression was indicated by a sensitivity of 78.4%, specificity of 66.8%, a PPV of 34.2% and NPV of 93.4%. The capacity to detect anxiety was indicated by a sensitivity of 77.3%, specificity of 56.6%, a PPV of 55.2% and NPV of 80.25%. Finally with respect to detecting general distress the following was obtained: sensitivity of 78.3%, specificity of 66.5%, a PPV of 59.7% and NPV of 82.8%. These results suggest that brief screening measures may be able to adequately rule out cases in which distress is not present, but are only moderately
successful in identifying those who are in distress and may be in need of further support services.

More recently, clinical researchers have sought to improve distress screening in cancer care through the incorporation of advanced technology. Clark and colleagues (2009) developed and implemented the ‘How Can We Help Your Family?’ screening instrument using touch-screen portable computer terminals. Whereas this project remains in its pilot implementation stage, it has demonstrated preliminary feasibility, has been easily adopted by patients, and is able to automate referrals to various health professionals. However, limitations of this approach have been identified, including a lack of psychometric or theoretical guidance in the development of the screening tool, resistance by front desk staff, and relatively extensive time needed for patients to complete all 41 questions. Despite these limitations, this study represents an important step in the use of advanced technology in screening for distress in a medical setting.

A research team in the United Kingdom recently reported the development and evaluation of a distress screening measure using item response theory (IRT), an advanced form of psychometrics that may possess a number of advantages over classical test theory in measure development and assessment. Researchers (Smith, et al., 2007; Smith, et al., 2009) evaluated a pool of 63 items that were gathered from widely used questionnaires to assess psychological distress in cancer patients. Whereas the authors reported good model fit, unidimensionality and identified IRT as an effective method of analysis, a number of limitations were noted. Given that questions gathered from distress questionnaires regularly target higher levels of distress and are designed to assess psychiatric disorders,
the full range of the distress continuum was not represented. Importantly, many cancer patients may endorse subsyndromal levels of distress and therefore a more comprehensive conceptualization of distress may be warranted. As previously identified, widely-used measures of distress, such as those drawn from by Smith and colleagues, neglect domains such as coping self-efficacy, social support and patient satisfaction in patient assessment. The authors concluded that more items were needed to assess patients across the full range of the distress continuum.

Finally, Thomas and colleagues (2009) reported the recent development and evaluation of the Distress Inventory for Cancer (DIC), a measure of distress that adopts a more comprehensive conceptualization of distress similar to that proposed in the current study. The authors sought to assess factors such as social support and medical distress (patient satisfaction) in addition to the more traditional elements of emotional distress. This measure was reported to possess appropriate internal, construct and convergent/discriminant validity. Importantly however, the DIC also demonstrated a predictive relationship with negative clinical behavior, with individuals judged as high distress a 2.58-fold increased risk of being lost to follow-up care or treatment adherence. This important extension of distress screening beyond traditional measures of depression and anxiety is critical for the development of valid and integrated screening in medical care. Once again however, the DIC fails to acknowledge the importance of coping self-efficacy, which the current research team has demonstrated to be a highly significant predictor of depression and quality of life in cancer patients and survivors (Philip, Merluzzi, Zhang, & Heitzmann, under review). Further, traditional psychometric analytic
methodology were adopted by Thomas and colleagues, thus limiting the potential utility of technology in provision of screening, in addition to the statistical limitations of classical test theory in measure development and assessment.

In summary, ultra-brief paper-based measures of distress remain the most widely used and available forms of screening, however such measures are relatively primitive tools with compromised clinical utility and a number of critical limitations. Distress measures such as the HADS rely upon a narrow definition of patient distress, focusing solely on the existence of clinically significant symptoms of depression and anxiety. The DT in contrast adopts a much more comprehensive model of distress; however this is only achieved through ambiguity. A patient is asked to endorse their distress level on a zero to ten scale with no further instructions, thus enabling them to respond without regard as to from which domain(s) of their life this distress may stem (depression, lack of social support etc.). Whereas this form of screening is inherently flexible, it provides no further information to health care providers as to the source of distress and thus requires further follow-up before an appropriate referral can be made.

As previously discussed, current measures also possess limited ability to identify positive cases of distress. This can place significant pressure on often-limited supportive care resources and provides further basis for the development and implementation of a more accurate and sophisticated screening system in cancer care. In addition to these important conceptual limitations, current widely used measures remain primitive in nature and fail to utilize modern technology and advanced psychometrics. The role of touch-screen computers, item-response theory, and computer adaptive testing has proven
effective in other domains (e.g. educational testing) but are yet to be fully explored in the provision of comprehensive health care.

The accuracy and utility of distress screening measures are frequently assessed in relation to other forms of patient-based self-report measures, such as validated depression and anxiety questionnaires or clinical interviews (Mitchell, 2007). The relationship between distress screening and biological measures, health behavior intentions and broader health outcomes such as quality of life, remains largely unknown. This is a critical shortcoming in the literature and must be addressed if distress screening is to become a reliable, valid and integrated component of patient care. The current study will seek to extend the development and assessment of distress screening measures in medical settings through preliminary exploration of behavioral intentions and prediction of quality of life.

Behavioral intention is most often conceptualized within the framework provided by the Theory of Reasoned Action (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975) and an extension of this model, the Theory of Planned Behavior (Ajzen, 1991). These models posit that individuals’ behavioral intention, which is associated with their likelihood of following through with a behavior, will depend on their attitude towards the behavior, the subjective norms associated with the behavior, and their perceived control or self-efficacy. Subjective norms consist of others’ perceived beliefs regarding a behavior and can be considered to be of greater or lesser importance depending on an individual’s assessment. Perceived control represents individuals’ beliefs regarding the degree of ease or difficulty they would encounter in performing the behavior. This model
has been applied to health-related behavior including, for example, condom use (Albarracin, Johnson, Fishbein, & Muellerleile, 2001), exercise behavior (Hausenblas, Carron, & Mack, 1997), addictive behavior and health screening (see Godin & Kok, 1996 for a review). The current study will examine patients’ request for a referral to support services and the relationship between this request and their assessed distress level. The intention to seek support services will be influenced by an individual’s attitude towards these services in cancer care and the perceived beliefs of others regarding these services. One can hypothesize that the stigma associated with mental illness in society (e.g., Thornicroft, 2008) may exert significant influence upon the intention to seek support for some individuals. This investigation will provide a basis for future research in behavioral intention and follow-through in accessing support services in cancer care.

1.5 Current Study

Throughout the fields of psychology and medicine there exists the convenient illusion of independence and isolation between constructs. The work of Descartes in the 17th century provided the foundation for the dualistic separation of mind and body on which the Western biomedical model was formed (Descartes & Voss, 1989). The field of psychology also adopts convenient divisions between constructs, a convention that enables the independent study of factors such as social support and depression to be undertaken, while still acknowledging that such factors are associated and will often impact each other. It is posited that a more comprehensive and inclusive conceptualization of distress may provide the most effective and sophisticated framework by which screening can be undertaken in a medical setting.
The current proposal will seek to evaluate the appropriateness of a comprehensive model of distress screening, as well as address many of the limitations identified in the preceding pages. This will be made possible through the evaluation of the Distress Screening System (DSS), a comprehensive and sophisticated measure developed by the Laboratory for Psychooncology Research at the University of Notre Dame. In contrast to the narrow definition of distress adopted by such measures as the HADS, this system was developed within a biopsychosocial framework (Andersen, 2002), a theory which posits that health status can be influenced by multiple levels of stressors (Suls & Rothman, 2004), including the biological domain, the psychological domain; and the social domain. The biological domain represents factors such as disease stage, immunoregulation, and physical symptoms and side-effects. The psychological domain represents such factors as emotional distress, intimacy, body-image, affect regulation, adjustment, and cognition; while the social domain includes employment/financial difficulties, social aspects of quality of life, impact of medical appointments and social support. There also remains no assumption of independence between such factors, with a comprehensive model of distress enabling various factors to be associated with each other and exert bidirectional influence. The DSS will seek to maintain the flexibility of the DT while enabling a greater level of information to be recorded through the use of advanced psychometrics, a broader conceptual model and potential future use of modern technology and Computer Adaptive Testing (Gardner, Kelleher, & Pajer, 2002; Petersen, et al., 2006).

In concordance with the biopsychosocial framework, it is proposed that in order for a brief screening measure to provide a highly specific, sensitive, and valid indication
of patients’ level of distress, it must incorporate information concerning not only
dividuals’ self-reported symptoms of anxiety and depression, but also factors such as
patient satisfaction, social support, coping efficacy and functional ability. Factors
influencing levels of distress have long been identified in clinical practice, as reflected in
the Psychosocial and Environmental factors associated with Axis IV of the DSM-IV
(APA, 2000) and in the broader empirical literature. The diagnosis and treatment of
cancer can influence multiple facets of an individual’s livelihood, including their ability
to work, socialize with friends and family, engage in hobbies (Strang, 1992), as well as
their overall quality of life. Impairments in functioning, often due to pain, have been
consistently associated with symptoms of anxiety, depression and general distress
(Fatone, Moadel, Foley, Fleming, & Jandorf, 2007; Kuzevli Yildirim, Uyar, &
Fadillioglu, 2005; Phipps, Braitman, Stites, & Leighton, 2008; Strang, 1998).
Importantly, research has also established that individuals’ degree of functioning can
predict their level of psychological distress over and above their stage of illness and
treatment approach (Graves, et al., 2007). For example, Hopwood and Stephens (2000)
examined factors associated with depression in individuals diagnosed with lung cancer.
The authors reported that 33% of those assessed had symptomatology indicative of
clinical depression and that these symptoms were associated with functional impairment
and severity of symptoms.

Psychological distress has also been associated with individuals’ level of social
support and satisfaction with interpersonal relationships. As discussed, a cancer diagnosis
can be associated with pain, uncertainty and fear, as well as economic hardship and
disruption to personal and professional roles. A patient’s support structure, including partners, friends and family members, can be important in managing challenges associated with the cancer experience, including providing emotional and financial support and assistance in attending medical appointments. Research has indicated that a lack of social support can in turn be associated with heightened symptoms of distress and impaired quality of life (e.g., Friedman, et al., 2006; Kugaya, Akechi, Okamura, Mikami, & Uchitomi, 1999; Whelan, et al., 1997). In a study of 94 men diagnosed with prostate cancer, Balderson and Towell (2003) reported a significant association between high levels of psychological distress and reported concerns regarding patients’ social and family relationships. Further, Brothers and Andersen (2008) reported a significant association between a lack of social support and increased symptoms of depression in breast cancer patients coping with a disease recurrence. In a study of patients diagnosed with head and neck cancer, researchers found that the size of an individual’s social network and support structure predicted symptoms of depression (de Leeuw, et al., 2001; de Leeuw, et al., 2000), with those patients who reported lower levels of support tending to report higher levels of depression. Finally, attendance at cancer support groups has been associated with lower levels of psychological distress (Weis, 2003).

A cancer diagnosis can also challenge personal coping resources. Research has reported that individuals who possess a high degree of coping capacity and engage adaptive coping strategies, also report lower levels of psychological distress. For example, more efficacious pain management strategies were associated with lower levels of distress, anxiety, depression and fatigue in patients diagnosed with breast cancer.
(Reddick, Nanda, Campbell, Ryman, & Gaston-Johansson, 2005). In contrast, avoidant coping techniques have been associated with greater distress and impaired quality of life in women undergoing chemotherapy (Lutgendorf, et al., 2000) and those diagnosed with lung cancer (Henoch, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2007; Walker, Zona, & Fisher, 2006). Further, researchers have established an association between a helpless coping style and depression in a group of head and neck ambulatory cancer patients, while an inverse association between patients’ self-efficacy for coping with cancer and distress has also been consistently reported (Lev, Paul, & Owen, 1999; Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001). Finally, individuals’ satisfaction with care has also been associated with their level of psychological distress (e.g., Bui, et al., 2005), as well as more general measures of quality of life (e.g., Von Essen, et al., 2002). Given the potential influence that these factors may exert on an individual’s level of psychological distress, screening measures that seek to accurately identify ‘at-risk’ patients must establish a comprehensive model of distress.

The proposed study will therefore assess a number of constructs that have been associated with distress in cancer; including depression, anxiety, social support, personal coping, satisfaction with care, and functional impairment, within a comprehensive unidimensional model of distress. This model will be compared to a bi-factor three-dimensional model constituting a primary distress factor and two secondary factors: emotional distress (depression and anxiety) and patient resources (social support, coping self-efficacy, functional ability and satisfaction with care) and a bi-factor seven-dimensional model representing each factor separately (depression, anxiety, social
support, coping self-efficacy, functional ability and satisfaction with care)(Figure 1.). Importantly, the latter two models will examine items as they are related to a primary distress factor and the hypothesized specific factors.

The Distress Screening System (DSS) was developed using rigorous psychometric methodology, as outlined in the measures section of this manuscript. It consists of 52 items that are endorsed on a five-point Likert-scale. Item response theory (IRT) will be employed to evaluate a comprehensive unidimensional model of distress against bi-factor three and seven-dimensional models. IRT is considered a modern form of psychometrics that possesses a number of advantages over traditional forms of analysis based on classical test theory. These advantages include the ability to estimate an individuals’ state/trait level (e.g. distress) independent of the number of items administered, thus allowing for potential application of Computerized Adaptive Testing (Wainer, et al., 2000); estimation of state/trait level based on item and person characteristics that are independent of the sample drawn from a larger population; and flexibility in regard to ongoing item and test development and administration to different groups and for different purposes (Embretson & Reise, 2000; Lipscomb, Gotay, & Snyder, 2005; Reeve, et al., 2007). IRT therefore represents a sophisticated and flexible approach to model evaluation and measure development that is hypothesized to result in greater accuracy in predicting distress and enhance the provision of comprehensive patient care.

The current study also sought to extend the current literature through examination of patients’ health behavioral intentions. Information will be collected regarding patients’
desire for a support service referral and the ability of the DSS to predict these factors will be examined and compared to current screening measures (DT, HADS).

The detection and treatment of cancer-related distress has been identified as a critical component of comprehensive care. Despite this, current measures are primitive in nature, utilize a narrow and limited conceptualization of distress, fail to take advantage of modern psychometrics and technology, and possess questionable accuracy that can increase staff and patient burden. These limitations compromise the ability of medical centers and health care professionals to provide effective and comprehensive cancer care to patients. Each individual possesses a unique constellation of stressors, coping abilities, and support networks that contribute to their reported level of distress and can therefore dictate whether further intervention is needed. In order to provide comprehensive care in a medical setting, screening measures must acknowledge the multifaceted nature of distress within a more comprehensive and sophisticated model than currently exists.

Through the evaluation of a comprehensive model of distress and extension of existing literature by incorporating behavioral intentions, the current study will seek to transform the screening of distress in medical care. As the role of distress in affecting disease progression and health becomes clearer, the need for a sophisticated, comprehensive, and refined model of screening is clear. Such a model, together with the consequent screening measure developed within this framework, will enhance the ability of health care providers to offer effective, patient-centered care and promote health and well-being.
Specific Aim I: Preliminary measure evaluation

The psychometric properties of the Distress Screening System (DSS) will be examined through the use of traditional descriptive statistics and exploratory factor analysis. Of primary importance is confirming that items developed to assess each construct (depression, anxiety, patient satisfaction, social support, self-efficacy, and functional ability) form coherent factors in preliminary analysis and possess adequate convergent and discriminant validity.

_Hypothesis:_ Items developed to assess each construct within the DSS (depression, anxiety, patient satisfaction, social support, self-efficacy, and functional ability) will form cohesive factors and possess adequate reliability and convergent and discriminant validity.

Specific Aim II: Model determination

The current study will examine the measurement qualities of the Distress Screening System and assess whether a unidimensional, bi-factor three-dimensional or bi-factor seven-dimensional model is most appropriate.

_Hypothesis:_ It is proposed that the unidimensional model will provide the most appropriate model fit as demonstrated by factor loadings, intercorrelations, model fit indices ($\chi^2$/df ratio, RMSEA, CFI, SRMR), and examination of variance accounted for in each model.

Specific Aim III: Parameter estimation and model evaluation

Once an appropriate model is identified, item response theory will enable parameter estimates to be generated and further model evaluation to take place. Residual
plots, standard errors and information curves will be examined on a category, item and scale level to further evaluate the identified model within an item response theory framework.

*Hypothesis:* It is proposed that the identified model will provide good model fit as demonstrated by acceptable residuals, excellent coverage of the distress continuum, and widely used model fit indices (e.g. S-X², Bock’s χ², and Q₁ statistics).

**Specific Aim IV: Enhanced predictive capacity of the Distress Screening System**

In order to extend research concerning psychological distress screening beyond prediction of self-report scales of depression and anxiety, the current study will examine the ability of the DSS to predict patients’ quality of life and request for a support service referral.

*Hypothesis:* It is hypothesized that the DSS will possess greater predictive capacity than two widely used measures of distress (HADS, DT) as measured by receiver operating characteristic (ROC) curves and area under curve analysis.
CHAPTER 2:

METHOD

2.1 Participants

Data from 492 individuals diagnosed with cancer were collected as part of the current study. 150 patients undergoing treatment were recruited through the Radiation Oncology Center at Memorial Hospital, South Bend, which is a member of the Northern Indiana Cancer Research Consortium. Recruitment was supported by the Director of the radiation center, the medical director, and with assistance from clinical staff. A further 342 post-treatment survivors were recruited from the Notre Dame Cancer Research Database, a database of individuals who have previously participated in research and consented to further contact from the Laboratory for Psycho-oncology Research. Participants completed the Distress Screening System, along with well-established and validated measures of distress, social support, self-efficacy for coping, patient satisfaction, quality of life and adjustment to disease. Patients recruited in all phases of the current research project received monetary compensation for their time and effort, as outlined in the Procedures section. Exclusion criteria for the current study included: 1) under the age of 18; and 2) unable to read and understand English.

2.2 Procedures

Current patients, who were recruited through Memorial Hospital, were
approached by hospital staff and provided with a brief questionnaire packet and consent form as part of their medical appointment intake. This packet contained three brief screening measures, including the Distress Screening System, and a short demographic questionnaire. It is estimated that these questions would take less than five minutes to complete, and patients were mailed a check for $10 to compensate them for their time. A trained member of the lab conducted a brief follow-up phone call with each participant. This was generally within three to four days of the packet being received; however those who endorse a distress level of four or greater on the Distress Thermometer, were called within two days of the information being received. This follow-up interview assessed coping resources of the patient, provided a referral to support services if needed, and enquired if the participant would like to be involved in the second stage of this study. If the participant assented, a further questionnaire packet was mailed to their home for them to complete and return using a postage-paid envelope. This packet contained measures of social support, personal coping, functioning, and satisfaction with care. A further $20 was mailed to participants who returned their completed questionnaire packet.

Post-treatment participants, who were recruited through the Notre Dame Cancer Research Database, were mailed a packet of questionnaires that included the Distress Screening System, a number of validated psychological measures, which are described below, and a demographic and health information form. It is estimated that it would take approximately 30 minutes to complete this packet, and participants were compensated $25 upon receipt of their completed forms. An identical protocol was followed for the
follow-up phone call to post-treatment survivors. Compensation for both groups of participants was provided through existing internal grants.

2.3 Measures

Distress. The Distress Screening System (DSS) consists of 52 items that assess domains associated with psychological distress and well-being. These include depression, anxiety, social support, coping efficacy, satisfaction with care, and functional status. An extensive literature search was conducted in order to identify current screening measures of psychological co-morbidity in the field. The validity of each measure in the literature was assessed and items that possessed consistent high factor loadings were identified. These items were then categorized within each domain to be assessed by the DSS (depression, anxiety, social support, coping efficacy, satisfaction with care, and functional status) and evaluated by the research team. Based on this knowledge, and consideration of existing literature concerning measure development (Clark & Watson, 1995), item development proceeded. Items were written to be clear and concise and to remain sufficiently general to be applicable to any disease state. A preliminary list of items were then submitted to a number of experts in the field for consultation and assessment of the suitability, clarity, and applicability of each item to the measurement of distress in medical settings. Once item wording was confirmed for all 52 items, a measure was created that would be simple and straightforward for patients to complete. Patients endorse the frequency of experiencing each item on a five-point Likert-type scale ranging from “never” to “almost always”. The DSS also contains a list of physical symptoms and external stressors which participants endorse as present or not present in the past seven
days, as well as whether they would like to speak to someone regarding this issue/symptom.

The Emotion Thermometer (Mitchell, et al., 2009) is a newly developed seven-dimensional tool to rapidly assess distress and burden across six domains, and help-seeking across one domain, using visual-analogue scales. Participants are asked to rate their level of distress, anxiety, depression and anger on an 11-point scale ranging from 0 (none) to 10 (extreme), along with the duration (0 = ‘Just today’ to 10 = ‘10+Months’) and burden (0 = ‘No effect on me’ to 10 = ‘Cannot function at all’) of this distress. Participants are also asked to indicate the degree to which they need help (0 = ‘Can manage by myself’ to 10 = ‘Desperately’). Pilot testing reports the ET to take approximately one minute to complete and has demonstrated moderate to good sensitivity and specificity in predicting depression (Mitchell, et al.).

*Functional impact.* The Sickness Impact Profile is a measure of the impact of any disease or disability (SIP, Karoly, 1985). It was designed for use with a variety of demographic groups, cultural groups, and severity levels of illness (Bergner, Bobbitt, Carter, & Gilson, 1981). The SIP is based on “statements describing sickness-related behavioral dysfunction from patients, individuals caring for patients, the apparently healthy, and health care professionals” The test-retest reliability for the measure is high ($r = .92$), as is the internal consistency ($r = .94$)(Bergner, et al.). The SIP has been shown to demonstrate convergent and discriminant validity when tested using a multitrait-multimethod approach (Bergner, et al.). It correlates strongly with other self-assessment measures of dysfunction, with clinical rating of sickness, and with clinical ratings of
dysfunction. The 45 items that constitute ambulation and mobility will be used to assess the physical impact of cancer and its treatments.

*Self-efficacy for coping.* The Cancer Behavior Inventory (CBI, Merluzzi, et al., 2001) is a 33-item measure of self-efficacy expectations about coping with cancer. Participants’ report their level of confidence for each item on a 9-point Likert-type scale (‘not at all confident’ to ‘totally confident’), which are added to form seven subscales. A total efficacy score is calculated by summing the scale values for all items. Alphas for the seven factors range from .82 to .89 and the alpha for the entire scale is .94 (Merluzzi, et al.).

*Satisfaction with care.* The Patient Satisfaction Questionnaire-18 (PSQ, Marshall & Hays, 1994) is an abbreviated version of the original longer PSQ-80. It assesses patient satisfaction with several domains of care, including: General Satisfaction, Technical Quality, Interpersonal Manner, Physician Communication, Financial Aspect, Time Spent with Physician, and Access and Convenience. Participants respond to each question on a five-point Likert scale, with higher scores indicative of increased satisfaction. This measure has demonstrated adequate reliability and internal consistency as compared to the longer version with the majority of subscale correlations above .90 and alphas above .73 (Marshall & Hays).

*Quality of life.* The Functional Assessment of Cancer Therapy (FACT, Cella, et al., 1993) is a 27-item measure of quality of life that contains four subscales: Physical Well Being, Social/Family Well Being, Emotional Well-Being, and Functional Well-Being. Individuals with cancer respond to a variety of questions by indicating on a five-point
scale (‘not at all’ to ‘very much’) how the items apply to their lives. The authors reported subscale alphas of between .69 and .82 and a total score alpha of .89 in a large heterogeneous sample of cancer patients (Cella, et al., 1993).

*Depression and anxiety.* The Center for Epidemiologic Studies-Depressed Mood Scale (CES-D, Radloff, 1977) is a 20-item scale that assesses current level of depressed affect. Patients rate the frequency of each item on a four-point scale that ranges from rarely (less than 1 day) to most of the time (5-7 days). A score of 16 is generally represents a moderately severe degree of depressive symptomatology (Myers & Weissman, 1980; Radloff). Internal consistency for this scale has been reported at .89 in a sample of cancer patients (Antoni, et al., 2001).

The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) is a 14-item self-report measure that has been designed specifically to assess depression and anxiety in persons with physical illness. Individuals respond to each item on a four-point Likert-type scale, including seven items that assess depression and seven that assess anxiety. Patients are asked to report the degree to which they agree with each statement in considering the previous week. Probable cases of clinically relevant psychological distress is indicated by scores of 10 or more on a single subscale, or a combined score of more than 16 (Zigmond & Snaith). Internal consistency estimates for item-total score correlations in a general outpatient sample ranged from .30 to .76 (Zigmond & Snaith).

*Social support.* The Interpersonal Support Evaluation List (ISEL, Cohen, Mermelstein, Kamarck, & Hoberman, 1985) consists of 12 statements concerning the perceived availability of potential social resources. The items relate to four categories of
support: tangible support, appraisal support, self-esteem support, and belonging support. The total score indicates the amount of support the person perceives as available. Internal consistency estimates have ranged from .77 to .86 for the total scale. Test-retest reliability was reported to be .87 for a four-week interval (Cohen, et al.).

**Stress.** The Perceived Stress Scale (PSS, Cohen, Kamarck, & Mermelstein, 1983) is a 10-item measure of the degree to which situations in one’s life are appraised as stressful. The Perceived Stress Scale has been used extensively in health research with higher PSS scores associated with failure to quit smoking, greater vulnerability to depression, and more frequent colds (Cohen, Towbes, & Flocco, 1988). The PSS has been endorsed as a psychometrically sound measure with “a respectable record of validity studies, including noteworthy biological correlates” (Monroe, 2008).

**Demographic and Health Information.** Information regarding participant’s age, employment status, income, education, religious preference, race, treatments, marital status, and health behaviors was obtained. Data regarding stage, time since diagnosis, type of treatment, number of follow-up medical visits since completing treatment, and other pertinent physical problems will be obtained from physician records with the permission of the participant obtained from a release of information form.

**Follow-up phone call protocol.** Participants were called and asked a series of questions related to their current level of distress and the desire for a referral to support services. Participants were reminded of the questionnaire they had recently filled out and informed that their answers to a three-minute survey would remain confidential unless they wanted the information shared with their physicians (at which point a separate
release of information was mailed to participants to complete). Information regarding patients’ current level of distress and their coping resources was collected using both open-ended questions and a ranking of common resources on a scale from 1-5 (or “does not apply”). Finally, participants were asked if they have accessed support services in the past and if they would like a referral at this point in time to community resources. If a patient indicated they would like a referral then information regarding support services was provided.

2.4 Proposed Analysis

2.4.1 Specific Aim I: Preliminary analyses

In order to investigate the preliminary structure, validity, and reliability of the Distress Screening System (DSS) traditional descriptive statistics were examined across items, subscales and the total measure. Central tendency (means, medians), spread (standard deviation, range), skewness, kurtosis and internal consistency were also examined as appropriate. Missing data was examined to determine the likelihood of systematic or random missing response patterns. The item correlation matrix and factor loadings were examined to explore whether the proposed domains (social support, depression, anxiety, self-efficacy, patient satisfaction, functional capacity) emerged as cohesive factors and to gather preliminary information regarding the loading of items. Convergent and discriminant validity were also examined for each of the factors using valid empirical measures, as detailed in the measures section.
2.4.2 Specific Aim II: Model evaluation and parameter estimation

The current study posited that in order to accurately identify distress in a medical setting it must be conceptualized within a more comprehensive model that currently exists in clinical practice or the empirical literature. The DSS has been developed within such a model, the biopsychosocial framework, and will seek to enhance the screening of distress through the use of this model and advanced psychometrics. Unidimensionality and local independence assume that a primary factor will account for item intercorrelations and that response to items will be independent of each other (Lord, 1980; Lord & Novick, 1968). Whereas it is acknowledged that in the context of complex constructs such as distress these assumptions are rarely satisfied in practice, they provide an important basis for model evaluation.

2.4.2.1 Model testing

Three models were examined in order to determine the appropriate model to move forward with in the current study. A unidimensional model was compared to a three-dimensional bi-factor model that conceptualizes distress as comprising a primary distress factor and two secondary factors: distress (depression and anxiety) and patient resources (self-efficacy, patient satisfaction, functional ability, social support). In addition, both models were compared to a bi-factor seven-dimensional solution that allows items to load on both the primary factor and the six individual factors (depression, anxiety, self-efficacy, patient satisfaction, functional ability, social support). This form of modeling allows items to load on both the hypothesized primary factor and additional group factors (Gibbons, et al., 2007; Gibbons & Hedeker, 1992; Immekus & Imbrie, 2008; Reise,
Morizot, & Hays, 2007) and has proven appropriate for assessing model fit in quality of life measurement (Gibbons, et al., 2007).

A number of structural equation modeling (SEM) fit criteria were assessed to evaluate overall model fit, in addition to consideration of item loading and intercorrelations. Although the chi-square statistic ($\chi^2$) is routinely assessed, it is well known to be sensitive to larger samples, such as that in the current study. Given that the $\chi^2$ statistic was significant, additional information regarding model fit was assessed from alternative fit indices. These include the $\chi^2$/df ratio, the Root Mean Square Error of Approximation (RMSEA), the Comparative Fit Index (CFI), and the Standard Root Mean Square (SRMR), which was assessed using the following guidelines. Values of between 2 and 5 for the $\chi^2$/df ratio are indicative of adequate fit (Marsh & Hocevar, 1985), while an RMSEA of less than .10, a CFI above .90, and an SRMR of up to .08 will also be considered appropriate fit indices (Browne & Cudeck, 1993).

In addition to SEM fit indices, item loadings were examined. The degree to which an item loads on the primary distress factor as compared to the secondary factor (e.g., patient resources) in the bi-factor three-dimensional model, or the individual factor (e.g. social support) in the seven-dimensional model can provide an indication as to the degree to which a unidimensional model is an appropriate assumption. Such a model would be represented by all items loading reasonably well (> .40) on the primary distress factor, a large ratio between the first and second eigenvalues, and a relatively high proportion of variance accounted for by the primary factor (> .20%).
2.4.3 Specific Aim III: Parameter estimation

Once an appropriate model was identified, item response theory (IRT) was used to further generate parameter estimates for each item and allow further model evaluation. Models developed using IRT enable estimates of item properties and participants’ latent state/trait levels to be established on the same metric, in this case, patient distress. IRT will provide information regarding the probabilistic relationship between individuals’ distress level and their response to a questionnaire item. For each item an estimation of discrimination (slope) and difficulty (threshold) parameters were generated. Item slope ($\alpha$) provides an indication of an item’s ability to discriminate between participants with varying levels of the target construct (distress), with a sharper rise between distress levels indicative of greater discrimination. The difficulty threshold ($\beta$) is the estimated distress level at which point a participant possesses a 50% chance of endorsing an item. These parameters are plotted as item/category response curves, with an individual’s distress level ($\theta$) on the X-axis and the probability of item/category endorsement on the Y-axis. In short, IRT provides a sophisticated psychometric framework by which an individuals’ distress level can be estimated by their pattern of responding to a one or more questions, rather than a total summed score as is normally examined in classical test theory.

Model parameters were estimated using Samejima’s Graded Response Model (GRM, Samejima, 1969) for polytomous response data. This model is a flexible extension of the two-parameter dichotomous response model that allows both item difficulty and discrimination to vary and was expected to provide appropriate modeling of data with the proposed sample size (Everitt & Howell, 2005; Hambleton, 1989).
this model, a participant’s response to an item is examined in the context of a Likert scale, with each response choice (e.g., ‘Not at all’ to ‘Very often’) represented by a category. The GRM therefore describes the relationship between a respondents’ given distress level and their probability of responding within a certain response category.

Item parameters ($\alpha$ and $\beta$) were generated using marginal maximum likelihood (MML) estimation and Multilog software (Thissen, 1991). Once generated based on the appropriate model (unidimensional vs. bi-factor vs. seven-dimensional) these parameters enabled residual plots to be generated and examined. Residual plots are a common method by which to examine the accuracy of predictions made by an IRT model. Residual plots are based on the potential difference between a participant’s expected response to an item or set of items (based on the estimated model parameters) and the observed response pattern in the raw data. These residuals can be examined at a category level (e.g., participants’ expected and observed response to the ‘Not at all’ option), an item level (participants’ expected and observed response to an item) and at a scale level (participants’ expected and observed response pattern to a set of items). Generally, standardized residuals within two standard errors are desirable, with those outside of this range indicative of poor fit and requiring further examination. In addition to examining residual plots, there are also a number of model fit indices within IRT that can provide further information. These include for example AIC, BIC, $S\chi^2$, Bock’s $\chi^2$, and Yen’s $Q_1$ statistic (Embretson & Reise, 2000; Kang & Chen, 2008; Lipscomb, et al., 2005) and in conjunction with residual plots provided an overall evaluation of model fit.
2.4.4 Specific Aim IV: Enhanced Prediction Analysis

The DSS will eventually be examined for use in conjunction with Computer Adaptive Testing (CAT). This program identifies the most appropriate items to administer to participants based on their response to previous questions and dynamic estimation of their trait/state level. This procedure enables different sets of items to be administered to participants based on their estimated level of distress, resulting in shorter adaptive tests and reducing patient burden. In order to establish the preliminary predictive capacity of the DSS, this measure was compared to widely used measures of distress (HADS, DT) and utilized all 52 questions of the item bank. Once the preliminary predictive capacity of the DSS is established, future studies will adopt CAT and seek to implement the DSS in a cancer care setting.

In order to extend research concerning psychological distress screening beyond prediction of self-report scales of depression and anxiety, the current study examined the ability of the DSS to predict patients’ request for a support service referral and quality of life. The two outcome variables were dichotomized to enable analysis based on Receiver Operating Characteristic (ROC) curves. Patients’ request for referral was also dichotomized into request and no request, while patients’ quality of life was dichotomized into high and low groups based on the median score. In order to examine the predictive utility of each measure, ROC curves were generated to provide the area under curve of the DSS, HADS and DT. Sensitivity describes the number of individuals with a particular condition who are identified as such (e.g., an individual with a low level of quality of life identified as such by the DSS). Specificity describes the number of
individuals without a particular condition who are identified as such (e.g., an individual with a high level of quality of life identified as such by the DSS). This information is captured in the frequencies of true positives, true negatives, false positives and false negatives across each measure. In test development and assessment, an acceptable trade-off between sensitivity and specificity is sought. In future work, ROC curve analysis will enable a cut-off score to be generated for the final version of the DSS at which the optimum trade-off between sensitivity and specificity is reached for prediction of quality of life and support referral.

The accuracy of each measure will be assessed through examination of ROC curves and subsequent Area Under Curve (AUC) analysis. AUC scores and confidence intervals will provide a qualitative indication of the accuracy of each predictor across both outcome measures. This comparison between the DSS and two widely used screening measures (HADS, DT) will provide an indication as to whether a comprehensive model of distress, as proposed in the current study, can prove more effective in predicting quality of life and distress-related patient behavior, and extend the current literature on screening and the provision of comprehensive cancer care.
CHAPTER 3:
RESULTS

3.1 Sample Demographics

There were 492 patients diagnosed with cancer who participated in the current study. The majority of patients were female (71.3%), married (59.6%) and Caucasian (68.6%) or African American (20.7%). The mean age of this sample was 61.41 years (SD = 12.92) with ages ranging from 20 to 89 years old. The majority of participants had completed high school (64.8%) and reported being employed (34.5%) or retired (45.8%). Reported income was below $25,000 for 30.3% of the sample, between $25,000 and $50,000 for 29.5%, and over $50,000 for the remaining 40.2% of participants. Patients were a combined sample of those currently undergoing treatment and post-treatment survivors. Those assessed in the current study were diagnosed with either breast cancer (48.9%) or prostate cancer (10.2%), followed by colon cancer (5.0%) and non-Hodgkins lymphoma (4.5%). Complete demographic information is contained below in Table 1.

3.2 Distress Screening System: Preliminary Analysis

The DSS requires participants to rate their level of agreement with 52 statements from 1 (“not at all”) to 5 (“almost always”) based on their experience over the past seven days. Items cover a range of domains associated with distress and coping with cancer. A possible scale range of 52 to 260 exists, with higher scores indicative of a greater level of
distress. Scores on the DSS can be added to provide an overall distress score, or can be expressed as five domain scores. These domains represent more specific factors associated with illness and distress and include Coping Efficacy, Emotional Distress, Functional Ability, Satisfaction with Care and Social Support. Twenty-six items of the DSS are ‘positively’ worded (“I was able to take care of myself”) and are therefore reverse scored to remain consistent with the entire scale. Initial analysis revealed less than 5% missing data with no apparent pattern or grouping to missing data. In accordance with Tabachnik and Fiddel (2006) it was deemed appropriate to implement mean substitution and rounding to manage missing data. Examination of Malhanobis values revealed only one individual to possess a sufficiently high score to warrant concern, which was found to be due to uniformly extreme responding across the entire measure. This individual was removed from further analysis.

The reported range of scores for the assessed sample was 54 to 195 for the Total DSS scale, with a mean of 107 (SD=28.9). Domain means and standard deviations are reported in Table 2, while correlations between the DSS subscales and the total scale are presented in Table 3. Analysis revealed that the majority of items on the DSS were identified as possessing a mild positive skew; however there were no items or domain scales that possessed significant departures from normality.

In order to assess the reliability or internal consistency of the DSS, Cronbach’s alpha was generated for the entire scale and for each domain. The DSS Total Scale possessed an alpha of .94, while DSS domain alphas ranged from .75 to .88, with the exception of the Coping Efficacy domain (Alpha = .64). Analysis of item-by-item alpha
identified a number of possibly problematic items (see section below), however item removal did not significantly improve overall or scale domain alpha scores, except in the case of Coping Efficacy. Removal of three problematic items from the original 12 (Items 9, 13, 31) resulted in a modest increase in alpha from .64 to .71.

Concurrent validity coefficients were examined in order to assess whether the DSS aligned with validated measures already utilized in empirical research studies. The DSS Total Scale demonstrated significant correlations with a number of validated health-related measures. These included measures of distress, quality of life, depression and disease adjustment and are presented in Table 4. Similarly, the association between DSS domains and validated measures were uniformly significant. These included the DSS Emotion Scale and the HADS ($r = .72$, $p < .01$) and CESD ($r = .69$, $p < .01$), the DSS Self-Efficacy Scale and the CBI ($r = -.55$, $p < .01$), the DSS Satisfaction with Care Scale and the PSQ ($r = -.47$, $p < .01$), the DSS Social Support Scale and the ISEL ($r = -.60$, $p < .01$) and the DSS Functional Ability Scale and the SIP ($r = .56$, $p < .01$).

### 3.3 Assessment of Dimensionality

The preliminary findings presented above provide the basis for continued examination of the DSS and exploration of appropriate model fit to the sampled data. The DSS will be examined within the context of item response theory, however before such analysis can take place it must be determined as to whether this measure can be conceptualized in terms of a unidimensional or bi-factor model. The current study sought to explore the fit of three possible models; a unidimensional model, a bi-factor three-dimensional model, and a bi-factor seven-dimensional model. Preliminary analysis of
scree plot data and eigenvalues revealed that between one and three factors would represent the most appropriate fit for the sampled data. The proposed seven-dimensional model was therefore not evaluated and model fit statistics were obtained through an exploratory factor analysis for the unidimensional and three-dimensional bi-factor models.

The unidimensional model proposed that distress could be conceptualized as a single cohesive factor with sufficient commonality across the five domains measured (emotional distress, self-efficacy, patient satisfaction, functioning and social support). The bi-factor model proposed that distress will once again form a common element across all five domains; however once this common element was removed, two broad factors would emerge: patient resources (self-efficacy, patient satisfaction, social support and functioning) and emotional distress (depression and anxiety).

Chi-square tests examine the discrepancy between observed and expected values based on a hypothesized model, with a significant result indicative of model misfit. The chi-square value for both models were significant and thus further evaluation was based on examination of model fit statistics, factor loadings, theoretically-based interpretability of item loadings and variance accounted for by each factor. The unidimensional model ($\chi^2 (1274) = 21844.37, p<.001$) possessed a $\chi^2/df$ value of 17.14, a CFI of .844, RMSEA of .181 and SRMR of .133. The factor loadings for the unidimensional model ranged from .12 to .87, with all but six of the fifty-two items demonstrating a loading of .30 or higher. The variance accounted for by the first factor was 28%, above the prescribed
cutoff recommended by Reckase (1979) as indicative of sufficiently unidimensional structure.

Examination of the multidimensional (three-dimensional) bi-factor model ($\chi^2(1173) = 5807.48, p<.001$) revealed a $\chi^2/df$ value of 4.95, a CFI of .965, RMSEA of .09 and SRMR of .057. Factor loadings were also examined for this model. Whereas a number of items loaded strongly and as predicted, overall the empirically based structure that was hypothesized by the bi-factor model was not present. A primary distress factor, along with secondary factors of depression/anxiety and patient resources were not established and there did not appear to be a coherent theme or content structure of item loadings overtly present. Items that possessed poor factor loadings across both models were noted and will be examined at the end of this section.

Evidence of uni- or multidimensionality in the sampled data was assessed in consultation with an expert in item response theory and model evaluation. A more complex model will always possess superior fit statistics when compared with a simpler model, and thus it was hypothesized that this would be the case in the current study. It was also predicted that factor loadings for the bi-factor model would represent a theoretically based structure that included emotional distress and patient resource domains in addition to the global distress factor. Whereas the model fit statistics were indeed superior to those of the unidimensional model, the factor loadings of the bi-factor model did not adhere to this hypothesized structure and thus further consideration was given to whether the unidimensional model was sufficiently unidimensional to permit examination within an item response framework. The level of variance accounted for by
the first factor exceeded recommendations put forth in the literature (Reckase, 1979), while the great majority of items loaded heavily on the first factor, with only a few exceptions falling below a cut-off of 0.2 and the majority exceeding 0.6.

Therefore, in consultation with statistical experts and based on a complete consideration of overall model fit statistics, theoretical interpretation of the proposed factor structure, item loadings and the level of variance accounted for by the first factor, it was deemed appropriate to move forward with a unidimensional model and examine the DSS within an item response framework. As will be discussed below, it is possible that alternative multidimensional models not examined in the current study may possess appropriate fit both statistically and empirically. This provides ground for future measure development and consideration.

3.4 Item Response Analysis

Multilog (Thissen, Chen, & Bock, 2010), Residplots (Liang, Han, & Hambleton, 2008a, 2008b) and SAS (SAS Institute Inc, 2009) were utilized in order to examine the item and scale properties of the DSS within the context of item response theory. Item parameter estimates were calculated in order to estimate expected and observed scores on the DSS based on the sampled data and a unidimensional graded response model (Samejima, 1969). A number of item and scale-level properties were examined in order to assess overall model fit and the ability of the DSS to estimate distress in a clinical setting. An examination of standardized residuals and chi-square analysis provides insight into model fit and the potential discrepancy that may exist between observed and expected scores on the DSS. Expected scores are derived from the item parameter
estimates and then compared to two sets of observed scores: those derived from raw data from participants (observed curve) and those simulated with the assumption that estimated item parameters and theta scores represent true values (simulated). These estimates are then grouped in order to provide mean scores at standard intervals of theta. Standardized residuals can then be calculated for each group of scores and plotted on a cumulative distribution graph (Figure. 3).

It can be observed that the number of residuals accumulate earlier and more consistently in the observed scores, representing more variability and a greater number of extreme values, than the simulated distribution. Whereas greater variability in sampled data is to be expected, the overall trend is maintained despite this departure from the hypothesized model. Whereas item based analysis is often emphasized in item response theory analysis, overall model fit statistics do exist within this framework. It was not possible to generate an overall model fit statistic based on the unidimensional model, possibly due to insufficient sample size given the large number of items and response categories of the DSS. This will be discussed further in the following chapter.

In addition to scale level analysis, it was revealed that all items possessed significant chi-square values, generally regarded as indicative of poor fit between observed and expected responding at an item level. It is important to note that items possessing multiple response categories, such as the Likert scale used in the current DSS, are represented by an item response curve for each response option. In order to ease interpretation and the evaluation of item functioning, these individual response curves are collapsed to provide an overall item response curve. Overall item response curves rarely
obtain non-significance when evaluated by chi-square analysis, and are therefore not necessarily indicative of poor item functioning and fit. The standardized residuals associated with each item were also examined. It is generally considered desirable that residuals remain within two standard errors of the predicted scores. In examining the DSS it was revealed that eight items met this criterion; with eighteen and thirteen items possessing one and two standardized residuals beyond two standard errors respectively. Twelve items possessed three or four standardized errors beyond this range, while one item (Item 10) possessed five. The majority of these errors were found to exist at particular points along the scale, including .4, 1.2 and 1.6.

Discrimination ($\alpha$) and difficulty ($\beta$) parameter values for each item are presented in Table 5. At an item level of analysis, discrimination ($\alpha$) parameters ranged from .21 to 3.37, with higher values indicative of a greater ability to distinguish individuals at a specified range of theta (distress level). To ease interpretation and for descriptive convenience, discrimination values are judged to be very low (.01-.34), low (.35 - .64), moderate (.65 – 1.34), high (1.35 – 1.69) or very high (>1.70)(Baker, 2001). It is important to note that a low level of discrimination is not necessarily indicative of a ‘bad’ item, only that such an item is not sensitive to variation in theta values. In responding to such items, individuals with different levels of theta (distress) would possess similar response patterns, thus providing limited information. Only one item in the current study (Item 9) possessed very low discrimination, with 44 of the 52 items possessing moderate (41%), high or very high (37%) discrimination. Those items within the very high discrimination range tended to draw from the domains of social support,
emotional distress and satisfaction with care. Items from the domain of coping self-efficacy were over-represented in the low and very low categories of item discrimination and therefore could be problematic, as will be discussed later.

The difficulty (β) parameter represents the point along the distress (theta) continuum at which an individual has a 50% chance of responding in the affirmative, and thus provides an indication as to where an item is most effective in its estimation. The difficulty of a 5-point Likert scale item is represented by four boundary location parameters (β₁ through β₄), each representing the probability of an individual at a particular theta value responding to this option or higher on the Likert scale. The difficulty of items in the DSS ranged predominantly from a theta of -.5 to 1.6, with most item responses existing in the moderate range. There was a broader spread of within item boundary parameters (from 1 to 4) in items from the functionality and self-efficacy for coping domains. A more restricted and consistent spread was observed in items from the domains of satisfaction with care and functional distress, whereas items from emotional distress and coping self-efficacy possessed a broader spread of boundary parameters.

These findings, in addition to the information curve that will be discussed below, provide an indication as to where on the distress continuum the DSS is most accurate in measuring. Thus, on a theta scale of -3 to 3, the DSS functions with the greatest level of accuracy within a range of -.5 to approximately 1.6. This range of theta tends to contain items whose discrimination and difficulty parameters function with the least degree of error. Item discrimination is relatively high and item difficulty parameters are also well represented across this range. Therefore estimates of participants’ distress (theta) are
most accurate within this range, while the DSS also possesses a greater ability to distinguish between individuals estimated to possess distress in this range. The clinical and empirical implications of this are discussed in the next chapter.

An example of an item with high discrimination and appropriate range is noted in Figure 4, while Figure 5 denotes an item with poor discrimination and a high level of error. In these figures, the vertical bars represent the standard error of the predicted mean score, based on item parameter estimates and the sample size at each theta location along the x-axis. If the observed means lie outside of this range then this is indicative of poor fit at a given theta value for that particular item.

An examination of standard errors associated with these boundary curve estimates can provide additional insight into the accuracy of estimates at each point on the Likert-scale. Analysis revealed three primary patterns: one group of items possessed relatively small standard errors across all four boundary curve parameters, a second group had consistently small standard errors across boundary curve estimates with the exception of the highest response category, whereas a third group possessed large standard errors across all response options. Consistent with previous results, items with consistently small standard errors were overrepresented by the domains of social support and emotional distress. The domain of coping self-efficacy possessed a number of items with consistently large standard errors across all response options. Items that were consistent with the exception of the highest response category represented items from domains of coping self-efficacy and satisfaction with care, and indicate that fewer participants responded to these questions in the extreme (“Almost Always” or “Not at all”).
The functioning of items in respect to discrimination and difficulty, and consequent accuracy of estimating the latent construct (theta), is reflected in the scale information curve (Hambleton, 1989). In Figure 6, the information curve for the DSS is presented for each interval of theta (information is inversely related to the standard error of measurement for theta). Similar to the range identified in analysis of difficulty and discrimination parameters, the range of theta in which the DSS is most accurate in estimating individuals’ distress levels is from -.5 to approximately 1.4, at which point there is a decline. The sharp increases or ‘spikes’ noted at the theta levels 1.8 and 3.0 are artifact of the graphing procedure and grouping of theta levels, and do not normally signify notable differences in scale functioning at these points. Participants’ theta estimates, which are based on item parameters and their observed raw responses, were examined in order to establish if they were contained within the range specified above, and thus whether the DSS is an appropriate measure in this regard. Examination of participants’ theta scores revealed that very few individuals possessed distress scores beyond 1.4, with the average distress score (theta) being -.23 (SD = .93), slightly below the midline for distress. A range of -2.62 to 1.57 was established. As would be predicted in the assessment of distress in a large convenience-based cohort of cancer patients and survivors, many individuals were estimated to possess low levels of distress, with approximately 40% below -.5. The clinical and empirical implications of this are discussed further in the next chapter.
3.5 Problematic Items

Prior to assessing the predictive capacity of the DSS, items identified as problematic were examined using a number of statistical approaches. The following items were identified based on poor correlations with domain and total scale items, alpha scores (.081 to .317) and factor loadings (.12 to .39) when assessed in relation to the DSS Total Scale and their respective domains.

Analysis based on item response theory above provided further evidence in assessing problematic items. It was confirmed that items 9, 21, 31 and 37 possessed unacceptably large standard errors and provided little information beyond that of more robust items. The items noted below tended to possess lower levels of discrimination and broader spread in boundary curves. The number of data points that lay outside of two standard errors in item response functioning ranged from one to four for the items identified. The content of problematic items and possible trends are discussed in the final chapter. Based on this multimodal analysis of items, the following items identified in Table 6 are noted as problematic and requiring further investigation in the development of the DSS.

3.6 Enhanced Predictive Capacity

In order to establish the predictive capacity of the DSS it was compared to existing measures of distress that are widely used in clinical and empirical settings. Based on item response theory guidelines, parameter estimates were utilized in order to generate a distress level (theta) score for each participant in the study. Participants’ scores on measures of distress (DT), anxiety and depression (HADS), quality of life (FACT) and
whether a participant was interested in a referral to support services were also collected.
The sample median on the quality of life measures was established to provide a
dichotomous cut-off score for the existence/absence of well-being. Area under curve
analysis was conducted to examine the ability of each measure to predict patients’ quality
of life and their interest in a referral to support services (Table 7). The receiver operating
characteristic (ROC) curve for each predictor and outcome measure are displayed below
(Figures 7 and 8).

As can be seen in the table below, the DSS and the two comparison measures are
very evenly matched in predicting quality of life and request for referral. The confidence
interval of the DSS overlapped with both comparative measures, with the HADS
demonstrating superiority in predicting quality of life and the DT negligible superiority in
predicting request for referral. All three measures were notably more effective at
predicting quality of life than request for referral to support services.
CHAPTER 4:
DISCUSSION

The diagnosis, treatment and long-term management of cancer have been associated with significant distress for approximately 30% of patients, predominantly in the form of depression and anxiety (Massie, 2004; Newport & Nemeroff, 1998; Stark & House, 2000). Despite the acknowledged need of support services to address cancer-related distress, there remain a number of empirical and clinical challenges to accurately identifying individuals in need. Current widely used screening measures are primitive in nature, narrowly conceptualize distress, possess questionable accuracy and require in-person clinical visits to assess patients. The current study consisted of the development and evaluation of the Distress Screening System (DSS), a measure that would seek to address these shortcomings and provide an empirically sound and clinically viable tool to identify patients in need of support services.

4.1 Summary of Key Findings

The preliminary psychometric properties of the DSS were examined through the use of traditional descriptive statistics and exploratory factor analysis. Generally, participants in the current study possessed the highest level of distress associated with their self-efficacy for coping, followed by emotional distress and a lack of social support. The least amount of distress was associated with participants’ reported functioning. The
DSS possessed significant correlations with validated measures of distress, depression, anxiety and quality of life in the expected directions. Importantly, these correlations, while significant, were not exact and thus it appears the DSS assesses a conceptually distinct construct from depression, anxiety, and quality of life. Further examination of the proposed domains of the DSS revealed significant and expected correlations with validated measures of self-efficacy, social support, functional ability, depression/anxiety and satisfaction with care. The internal reliability of the DSS and the individual domains were adequate, with the exception of the self-efficacy domain that possessed a lower than expected internal reliability of .64. This may be indicative of poorly constructed items or unexpected item functioning and thus will be examined in greater detail in a later section of this chapter. These preliminary findings suggest that the DSS is a psychometrically sound measure and that majority of items functioned as hypothesized.

Once the preliminary psychometric properties of the DSS were established, the current study sought to examine whether a unidimensional, bi-factor three-dimensional, or bi-factor seven-dimensional model provided the most appropriate fit for the sampled data through exploratory factor analysis. This structure of analysis was designed to guide the next stage of measure evaluation within an item response framework. Preliminary examination of data revealed that a one, two or three-dimensional model would be most appropriate and therefore the seven-dimensional model was excluded from further analysis. Whereas it was hypothesized that a multidimensional bi-factor model would possess superior fit statistics to a unidimensional model, it was also predicted that factor
loadings would represent the theoretically based bi-factor structure that included emotional distress and patient resource domains in addition to the global distress factor. The factor loadings of the bi-factor model did not adhere to this structure and thus further consideration was given to whether the unidimensional model was sufficiently unidimensional to examine within an item response framework.

The level of variance accounted for by the first factor exceeded recommendations put forth in the literature (Reckase, 1979), while the great majority of items loaded heavily on the first factor. Therefore, in consultation with statistical experts and based on a complete consideration of overall model fit statistics, theoretical interpretation of the proposed factor structure, item loadings and the level of variance accounted for by the first factor, it was deemed appropriate to move forward with a unidimensional model and examine this model within an item response framework. As previously noted, it is possible that an alternative multidimensional model may fit the DSS both statistically and empirically. Preliminary examination of factor loadings did not reveal a cohesive or obvious pattern of item loadings; however this provides ground for future measure development and examination.

Once these multiple sources of information were taken into consideration, and in consultation with a statistical expert, it appeared that distress could be conceptualized as a sufficiently unidimensional construct encompassing multiple sub-domains of distress. It was therefore deemed appropriate to move forward with the investigation of the DSS within the framework of item response theory. Once an appropriate model was identified, item response analysis provided a sophisticated framework by which to further assess the
psychometric properties of the DSS. Such analysis provides important information regarding the functioning of an item within a scale, as well as a preliminary foundation for future computerized adaptive testing, one of the key advantages of scale development through item response theory (Wainer, et al., 2000). Overall, item response analysis revealed the majority of items across domains to function well, providing further evidence of the ability to conceptualize distress as a rich unidimensional construct.

A number of sources were examined to evaluate the psychometric properties of the DSS and its ability to assess distress, including residual plots, standard errors and the scale information curve. The vast majority of items in the DSS possessed moderate to very high discrimination levels, indicative of the ability of an item to distinguish between participants at various levels of distress. These items represented each assessed domain, most notably the domains of social support, emotional distress and satisfaction with care, while items with lower levels of discrimination were over-represented in the domain of self-efficacy for coping. Similarly, items were also distinguished by the variability in the difficulty of item response, or where on the continuum an item response option functions most effectively. The domains of emotional distress and coping self-efficacy tended to possess items that functioned across a broader range, while items from the domains of functional distress and satisfaction with care possessed a more restricted range of functioning. The content of these items and possible reasons for poor discrimination are examined in greater detail below. Importantly, each of the hypothesized domains of distress, with the exception of self-efficacy, were represented by items that performed well within an IRT framework.
Items for which few people responded in the extreme (“Almost Always” or “Not at all”) were overrepresented in the domains of coping self-efficacy and satisfaction with medical care. This may indicate that that these questions did not lend themselves to ‘all or nothing’ evaluations. It is likely that patients will meet with a number of health professionals throughout the trajectory of care, including the return to primary care once their cancer is treated. It may therefore be likely that patients may have been more or less satisfied with various member of their care team, and thus unable to respond in absolutes. A number of questions within the coping self-efficacy domain asked participants to evaluate their use of coping strategies or implementation of behavior changes. Once again, given this question content, it may be expected that fewer individuals would respond in the extreme.

One primary advantage of item response theory is that the precision or accuracy of a scale is not uniform across different levels of the latent variable (distress). As predicted, the accuracy of the DSS was compromised at the extreme end of low distress and high distress where fewer participants responded. The DSS was found to function most accurately and effectively, and with the least degree of error, at levels of distress ranging from average to moderately high. Many respondents endorsed levels of distress within this range, and the midline shift to the distress end of the continuum is consistent with a scale intended to identify individuals in need of support. Items that performed well in this range generally possessed high levels of discrimination and would be thus better able to distinguish between individuals reporting different levels of distress. In the evaluation of clinical distress however, it must be acknowledged that the many patients
coping with cancer adjust well and are resilient, a fact borne out by the distribution of participants below the midline of the scale. A careful balance must therefore be sought between the development of a clinically relevant scale that is accurate at moderate to high levels of distress (rather than those who report little or no distress), and one that possesses a rudimentary level of accuracy across the entire spectrum of distress.

In order to extend research concerning psychological distress screening beyond prediction of self-report scales of depression and anxiety, the current study examined the ability of the DSS to predict patients’ quality of life and request for a support service referral compared to two widely used screening tools. Contrary to prediction, the broadened conceptualization of distress and use of item response theory did not result in a significant enhancement in the predictive capacity of the DSS. In the prediction of patients’ quality of life, the HADS performed best, although results were largely comparable between all three measures. Further, in the prediction of a patient’s desire for support service referral, the DT performed best. Once again however, the performance of all three measures was largely equivalent.

4.2 Problematic Items

Preliminary analysis and evaluation revealed the DSS to be a psychometrically sound instrument with hypothesized associations with validated measures and adequate internal reliability and item response functioning. Whereas the majority of items performed as expected, a number were identified as psychometrically weak and therefore may be indicative of poor item construction or unexpected item functioning. These items tended to possess less robust associations with respective validated measures, poorer
discrimination parameters and functioned over a much broader range than more effective items. These items tended to be over-represented in the coping self-efficacy domain, whereas others were phrased to possess a double negative in patients’ responses. More effective items tended to be more straightforward in phrasing and were well represented in the domains of social support, satisfaction with care and emotional distress. A closer examination of problematic items is provided below.

Four items identified as psychometrically questionable (9, 31, 13 and 36) asked respondents to consider action-orientated changes in the past seven days. For example, question 13 concerns what extent participants had ‘actively done things to cope’, while question 36 concerns whether or not they had ‘begun or maintained a healthy lifestyle change’. It is possible that given the relatively short time frame assessed by the DSS, questions such as these concerning changes in behavior or action-orientated coping may not be appropriate for the given time frame. For example, an individual may be engaging in adaptive behaviors that these items target, but may not have begun or engaged in them in the past seven days, thus prompting them to possibly answer negatively to such an item. The assessment of coping within the context of distress screening may therefore require further consideration in regard to time frame and item wording.

In addition, items 9 (‘Spent time thinking of ways to cope with my illness’) and 31 (‘Tried new ways of dealing with my illness’) did not function as predicted. It was hypothesized that the endorsement of such items would be associated with a reduced level of distress, indicative of active coping mechanisms. However, upon investigation it was found that these items in fact were associated with higher levels of distress. It is
possible that the endorsement of these items represented the need to invoke coping mechanisms to manage elevated levels of distress or challenges.

Items 21, 24, 30 and 40 contained negative queries (e.g. ‘Was not able to do some things I enjoy’), thus requiring participants to respond to a double-negative if endorsing ‘not at all’ on the provided Likert scale. It is possible that this created confusion and was not effective in assessing individuals’ true response to such items. If these items were to be kept, possible rewording to a positive framing or editing of the Likert scale choice may be necessary.

Finally, question 37 concerns the frequency with which participants asked for help (‘asked for help when needed’). The reason for the poor functioning of this item is difficult to identify, as it is simply worded, is a concept addressed in validated social support measures (e.g. Cohen, et al., 1985), and increased social support is routinely associated with lower levels of distress. It is possible that a patients’ stage of illness may impact the differential functioning of this item. Current patients may feel that is more acceptable for them to request help, and thus respond differently to survivors, who may feel that they should be able to manage challenges independently. Indeed, preliminary work by the author has found that the influence of social support may lessen significantly over time as individuals are expected to return to pre-cancer functioning and take greater responsibility for any ongoing symptoms (Philip, et al., under review). Given the current study assessed a sample of both patients and survivors, future studies would be needed to establish the influence of treatment status on item functioning and the relationship between social support seeking and distress.
The poor functioning of a number of self-efficacy for coping items, as well as the
domain as a whole, raises the question as to whether this is component of patient distress
as presently conceptualized. Self-efficacy for coping in the context of cancer has shown
strong and consistent associations with depression, quality of life and adjustment to
disease (Merluzzi & Martinez Sanchez, 1997; Merluzzi, et al., 2001); however it may not
be a suitable construct for assessing distress in the framework of time-limited screening.
The propensity to cope may represent a more stable and enduring characteristic that
participants find more difficult to conceptualize as a short-term variable. The inclusion of
a self-efficacy domain within the DSS therefore requires further examination and
consideration.

Therefore, there remain a number of changes that could be incorporated into a
revised version of the DSS in the future. The use of negatively framed items may not be
appropriate, while the utility of assessing changes in coping strategies within the brief
time frame of the DSS may not be possible. Relatively speaking however, these
problematic items represent a small number of the total fifty-two items of the DSS.
Future consideration and possible item revisions could potentially enhance the
psychometric properties and clinical utility of this measure.

4.3 Empirical and Clinical Implications

In order to place the current results within a broader context and to explore the
clinical and empirical implications of this study, one must evaluate not only the
psychometric properties of the DSS, but its potential clinical utility. The current study
sought to expand the conceptualization of distress beyond the routine assessment of
depression and anxiety observed in widely used screening measures such as the HADS (Zigmond & Snaith, 1983). It was hypothesized that patient distress was not synonymous with clinical symptoms of depression or anxiety, but instead was a broader construct more representative of a patients’ experience. Distress in this context could not only result from heightened symptoms of depression or anxiety, but also from impairment across a range of psychosocial domains, including lack of social support or self-efficacy, or dissatisfaction with medical care. In this context, it would therefore be possible that an individual may be distressed by a loss of social support or frustration with medical care, without necessarily endorsing symptoms of depression or anxiety.

The DSS therefore sought to capture a patients’ experience across a range of empirically derived domains that have been associated with distress. The extension of distress beyond symptoms of depression and anxiety to represent a broad and coherent construct appears to possess preliminary psychometric validity, with the current study establishing evidence for a unidimensional model of distress within traditional and item response theory frameworks. This measure may therefore represent a more nuanced version of the DT (Roth, et al., 1998), which provides patients with a 10 point visual analog scale and no pre-determined definition of distress. Therefore, with no predetermined definition provided, a patient could conceptualize distress as a lack of social support, or impaired self-efficacy, and complete the zero to ten scale as such.

One possible criticism of measures such as the DT is that such a vague conceptualization of distress reduces the clinical utility of a measure or could create difficulty in a clinical setting in which health providers are endeavoring to establish a
clear conceptualization of a patients’ experience. A further criticism exists that such vagueness could result in a greater degree of false positive identification of patients and wasted clinical resources. For example, if an individual was momentarily distressed due to frustration in locating the clinic, and were asked to complete the DT, it is possible that they may rate sufficiently high to be identified as ‘distressed’. Were further responses regarding the nature of this distress elicited, it is possible that such a patient would not meet criteria for follow-up.

The DSS therefore sought to maintain a broad conceptualization of distress, thus enabling a range of psychosocial domains to be assessed, while employing a more nuanced approach than the DT. It was hypothesized that this would improve the predictive capacity of this screening instrument, provide information regarding a patient’s experience, and ultimately enhance its clinical utility. Importantly, the broadening of distress conceptualization and more nuanced approach must be undertaken with consideration of clinical practice and patient burden. It would not be feasible or practical to elicit information from each patient using a 52-item measure assessing a number of potential domains of distress using traditional methods of data collection (i.e. paper and pencil). It was for this reason that the DSS was developed within the framework of item response theory, thus providing the foundation to develop a computer adaptive test that would select items judiciously based on a patient’s response pattern. This format has been shown to reduce participant burden without sacrificing the level of information garnered by a measure (Embretson & Reise, 2000; Wainer, et al., 2000).
Item response theory has become increasingly popular in the development and evaluation of health outcome measures (Cook, et al., 2007; Walker, Bohnke, Cerny, & Strasser, 2010). This is particularly notable in research concerning the assessment of quality of life (Cella, Chang, Lai, & Webster, 2002; Gershon, et al., 2003; Petersen, et al., 2006; Petersen, et al., 2010), a factor frequently examined in the empirical research and clinical care of cancer. Indeed, in research similar to the current study, Pagano and Gotay (2006) examined quality of life as a unidimensional construct in cancer care. In order to explore this hypothesis, the authors examined items from a range of quality of life measures within an IRT framework, reporting that a group of items demonstrated sufficient unidimensionality and coverage of quality of life domains. Similar to the current study and the poor performance of self-efficacy, the authors reported that one domain (cognitive functioning) was not be represented adequately by high performing items.

Further, and as previously noted, item response theory and computer adaptive testing has been successfully adopted in the domain of health outcomes research, most notably in the form of the Patient Reported Outcomes Measurement Information System (PROMIS, Reeve, et al., 2007). This ambitious, collaborative endeavor funded by the National Institutes of Health has sought to develop valid and reliable outcome assessment measures across a wide range of health-related domains. This database of measures is freely available to researchers, remotely accessible online and utilizes item response theory and computer adaptive testing to deliver brief, valid and reliable assessments. The potential for PROMIS to provide tools that could be utilized in a patient screening
context is yet to be fully explored. Should the DSS demonstrate clinical utility through further development and evaluation, it could potentially fit within the framework of the PROMIS database and provide clinicians and researchers with an effective, brief distress-screening tool.

Importantly, the potential of web-based remote administration of a screening tool such as the DSS is critical in addressing the changing needs of cancer care. The growing number of cancer survivors in the United States, along with increased understanding of cancer etiology, has gradually shifted cancer from an acute disease state to a chronic condition requiring on-going management. Post-treatment follow-up care is often less-than-adequate due to a care system that is designed to most effectively manage an acute disease state. Patients’ long-term care is often managed by primary care physicians who may not possess appropriate experience in treating psychological and physiological sequelae of cancer care. Efficient, remotely accessible, and accurate patient tracking methodologies may be most effective in maintaining sufficient contact with survivors to ensure that post-treatment effects warranting specialized cancer care can be provided.

The DSS sought to address this growing concern through adoption of advanced psychometrics and a foundation that could be readily deployed through a web-based portal. This format would ideally increase accuracy of screening identification of co-morbid distress, provide a forum by which patients could alert providers to ongoing concerns and symptoms, and enable providers to track long-term outcomes of cancer care.
Further, the frequently intense nature of cancer treatment, which can involve months of contact with a cancer care team and disruption of personal and professional livelihoods, can come to an abrupt end with the completion of treatment (Hewitt, et al., 2005). Survivors have often reported the difficulty of such intense relationships coming to a close, and the expectation that the patient now return to their pre-cancer lifestyle and responsibilities (Hewitt, et al., 2005). Whereas most patients are able to transition without significant psychosocial distress, the potential to maintain a limited degree of contact with a care team and center through web-based technology my represent an important component of follow-up care and comprehensive survivorship services.

Preliminary investigations by the Laboratory for Psycho-oncology Research at the University of Notre Dame have revealed a high percentage of long-term survivors report ongoing physiological and psychological sequelae to their cancer treatment (Philip & Merluzzi, in preparation). Despite the high prevalence of physical and psychosocial issues, only a minority of patients expressed interest in addressing these concerns with a health professional. A number of barriers may exists, which will be explored in detail below, but may include stigma associated with mental health care (Thornicroft, 2008), geographical and logistical separation of support care offered, or previously unsuccessful treatment of long-term effects. Whereas the reasons for such reluctance require further exploration, it is possible that physical and psychosocial concerns remained untreated when a patient loses contact with a primary cancer care team soon after treatment concluding, thus not providing the forum to address long-term concerns.
In order to evaluate the ability of the DSS to address challenges associated with the changing face of cancer care, the current study sought to move beyond the prediction of depression and anxiety in a cancer population. The majority of screening measures have been evaluated through their ability to predict depression and/or anxiety as defined often by a second self-report measure (Mitchell, 2007), or more rarely, a clinical interview (e.g. Houts, Lipinski, Olsen, Baldwin, & Hasan). Whereas this is an important component of measure development and evaluation of clinical utility, it is based on a restricted conceptualization of distress and is unable to speak to potentially more important clinical outcomes, such as a patients’ desire for support services. The current study therefore sought to evaluate the DSS and two widely used screening measures in their ability to predict patients’ quality of life and desire for support service referral. As reported, there were relatively little difference in the performance of these three measures in predicting quality of life and desire for support service referral. In considering the implications of these results in the current study, it is important to note a number of caveats.

The use of receiver operating characteristic curve analysis to evaluate the predictive accuracy of a measure relies upon the defining of a dichotomous outcome factor, for example the presence or absence of disease. Whereas this process can be straightforward in research involving clear indicators of presence and absence, through a blood test or gold-standard measurement, it is more difficult in circumstances where no such standard exists. A significant challenge in the current study was the identification of a ‘gold-standard’ measure of distress by which to evaluate the predictive capacity of the
DSS and the two validated screening tools. Previous work in this empirical domain has conceptualized distress as the existence of symptoms of depression and anxiety (Mitchell, 2007), thus providing the basis for the use of valid clinical measures or a structured diagnostic interviews as ‘gold standard’ indicators of whether a condition is present or not. The current study, however, sought to expand the conceptualization of distress beyond that of depression and anxiety in order to improve screening accuracy. Whereas it is hoped that this would enhance the clinical utility of screening measure, it also presented a challenge in assessing such a measure, as there exists no gold-standard measure of distress as defined in the current study.

Quality of life represents a construct most closely aligned with the broader conceptualization of distress in the current study, although not identical. Based on the existence of valid and reliable measures of quality of life in cancer, it was decided that it would represent an appropriate outcome by which to assess the DSS. This was not without challenges however. Quality of life is conceptualized as a continuous variable, whereby a patient is considered to have a greater or lesser degree of quality, rather than a definitive point at which they are considered to possess or not possess quality of life. In recognition of the continuous nature of this variable, there exist no valid or accepted cut-off scores in the literature that could be used to define the presence and absence of quality of life in ROC curve analysis. Thus, in the current study, a median split was used to define presence versus absence of quality of life and to enable analysis to proceed. Whereas this is less-than-ideal in assessing the DSS, quality of life represents a construct
much more closely aligned with the conceptualization and goals of the DSS than validated depression and anxiety measures.

This study also sought to extend the current literature on distress screening beyond prediction of self-reported measures of mental health, and assess the capacity of the DSS to identify individuals who were interested in support service referral. As discussed, this is an important consideration given that many individuals who are identified by screening measures may not be interested in further attention or services, thus resulting in inefficient use of clinical resources and providers’ time. A measure that can more readily identify individuals who would welcome further attention from health providers could guide the allocation of limited clinical resources. Therefore, individuals in the current study were surveyed via phone to assess their level of interest in a support service referral or additional information.

Once again, the DSS provided no significant benefit in the prediction of support service referral, however a number of challenges were evident in utilizing referral desire as an outcome measure. Most notable in the current study was patients’ lack of interest in referrals or additional information, regardless of their reported level of distress, physical symptom burden or psychosocial issues. A number of reasons for this reluctance may exist, each of which provide fertile ground for future research. Firstly, a stigma is still often associated with mental illness and psychological services, particularly amongst older generations. This stigma can result in individuals being unwilling to engage in supportive services or discuss referral options, and may partly explain the low number of interested patients in this study. Further, the logistical process by which support services
are often structured, as was the case in the current study, may have been an additional barrier. In many urban and rural oncology centers, patients are referred elsewhere in the hospital or in the city to receive psychological services. This serves not only as a logistical barrier, but can also reinforce the impression that such services are separate from their overall medical care, and therefore less important. This was indeed the case in the current study, whereby patients who were interested in a referral were given the details of an independent entity elsewhere in the city. Whereas the referral point was one with an excellent reputation in the community, the geographical separation and specialized mental health service focus, may have represented an important barrier to patients interest in further care.

Finally, the current study did not explore whether patients had received previous care for distress, depression, anxiety, or physical symptom burden. Many involved in the study were long-term survivors, and therefore it possible that they may have sought treatment for chronic physical or psychological complaints in the past, and they may have not been helpful. In addition, cancer treatment can be a traumatic and harrowing experience for a patient, and thus for some, they may have no interest in further visits to medical settings, or discussing their cancer and its long-term impact, regardless of ongoing symptom burden. Barriers to support service utilization have been explored in cancer care settings and must be addressed in the provision of effective care (e.g. Matthews, Corrigan, & Rutherford, 2003; Patrick, et al., 2004; Weinberger, Bruce, Roth, Breitbart, & Nelson, 2011). They represent a challenge to clinicians and researchers and provide grounds for the development of service structures that reduce barriers to
comprehensive care and promote disease adjustment and enhanced quality of life. It will be important in future research to assess the impact of having inclusive coordinated support services within the context of cancer treatment and distress screening, and ultimately to address potential long-term difficulties when they arise during treatment.

The results of the current study raise a number of questions, perhaps the most important of which in the context of this study’s results, is whether a single-item measure such as the Distress Thermometer is adequate given the complex and challenging task of detecting distress. The ambiguous nature of the DT, which does not define distress and instead allows patients to define it in their own terms, provides a degree of flexibility despite the limited nature of the information it provides. The DSS sought to assess the full spectrum of distress, therefore matching the broad nature of the DT, while providing information on specific domains of distress to health care providers. Whereas the psychometric properties of this measure appeared adequate, this measure did not provide a more effective prediction of patients’ quality of life or desire for support services as hypothesized. Importantly, if one was to utilize the paper-and-pencil DT, there remains the significant challenge of assessing survivors once they have ceased regular clinical visits. This of course may be possible through the inclusion of the DT within a web-based portal. Alternatively, the PROMIS initiative (Reeve, et al., 2007) provides a computer adaptive test bank of 29 items designed to cover a number of domains of mental and physical health. This is currently available for primarily research purposes via a web-portal, but could possibly be adapted to function as a clinical instrument for assessing and screening cancer patients during and after treatment.
4.4 Limitations

Whereas the current findings provide important information regarding the nature of distress and distress screening in a cancer care setting, they must be considered in light of a number of limitations. The cross-sectional nature of the current study did not allow for patient distress, its impact on care and its relationship to other clinical-variables to be explored over time. This represents the gold-standard in examining patient outcomes in a disease such as cancer, as variables such as coping self-efficacy, distress and social support for example, may change as a patient progresses through different stages of the illness trajectory (Philip, et al., under review). In addition, the current study assessed both current patients and cancer survivors, two groups that may possess different response tendencies to the questions posed on the DSS. Future development of the DSS screening tool with a more representative sample would need to examine potential differences between patient groups, as well as the influence of demographic and disease factors such as ethnicity, age, gender and disease site.

In addition to sampling limitations, it is also important to note that the current study explored only certain hypothesized models for the DSS. These models were empirically based; however the unidimensional and bi-factor models constitute only three possible options. It is possible that an alternative empirically-based multidimensional model may be more suitable and thus there remains ground for further research and consideration. Indeed, preliminary examination of model fit statistics of the three-dimensional bi-factor model within an item response framework revealed encouraging results for pursuing this line of investigation. Exploratory analysis revealed the
unidimensional model to possess an Akaike Information Criterion (AIC) of 59220.33 and a Bayesian Information Criterion (BIC) of 60311.93. In comparison, the bi-factor model possessed an AIC of 57151.39 and a BIC of 58461.31. The model with lower AIC and BIC scores represents a more appropriate fit. Whereas further examination of the bi-factor model was not within the scope of the current study, there remains potential for further development and exploration of empirically-based multidimensional models. In addition to model evaluation, the current study constituted the first stage of development and evaluation of the DSS, and therefore future work could examine the possible rewording or removal of problematic items.

Whereas the prediction of a patients’ request for referral information represents an important step in the assessment of screening instruments, the current study was not able to implement a perfect measure of patient desire and motivation and the low referral rates must be considered. Firstly, due to the assessment of both survivors and current patients, and the context of a University-based survey study, referral information was not given in the context of a patient’s current care or associated with their care provider. Instead, referrals were managed through the utilization of a well-known cancer support service entity in the local area. It is important to acknowledge the possible decrease in participation due to the geographic and logistical separation of supportive care services, along with barriers previously discussed such as stigma. Whereas measures were taken to minimize the possible impact of stigmatization through wording of questions and the provision of information, this may still have played a role in the low referral request rates in the current study.
4.5 Future Directions

Based on the results of the current study, the preliminary version of the DSS appears to contain sufficient quality items to accurately assess distress across a range of empirically based domains. The next stage of development would involve the assessment of the DSS as a viable computer adaptive clinical tool, enabling the multifaceted nature of the distress to be assessed without undue patient burden. A similar research paradigm to that of the large-scale PROMIS project could be used to guide development of the DSS as it is expanded to include participants from a range of geographical locations, ethnic and cultural groups, and at different stages of the illness trajectory.

Ideally, the role of distress screening would be assessed within a comprehensive and longitudinal framework, primarily based on a biopsychosocial model of exploration. A patient’s standing on a range of physiological, psychological and social factors would be simultaneously assessed over time, along with their desire for, and use of, health care and support services. This framework would provide the opportunity to fully explore the potential role of distress screening in guiding patient care and its influence on outcomes across the illness trajectory.

The current study sought to advance the empirical domain of distress screening assessment through incorporation of quality of life and patient preference information. In order to gain a complete understanding of the nature and role of medically co-morbid distress, future investigation may involve exploring the relationship between widely used distress measures and biomarkers of stress. This could include generalized markers of stress, such as cortisol, more specific immunoregulating substances such as cytokines
(e.g. IL-6, IL-10), or measures of sympathetic and parasympathetic tone such as heart rate variability. As science begins to regularly utilize these physiological markers of health and stress, along with more recent additions to study protocols such as telomere length and epigenetics, the remain a wide range of viable frameworks by which to assess and clarify the validity and clinical utility of screening tools.

A significant minority of patients diagnosed with cancer will experience clinically relevant levels of distress during the trajectory of their illness. The need to accurately and effectively identify patients in need of support is widely acknowledged; however a number of issues may compromise this effort. Many screening tools fail to utilize modern psychometrics, possess narrow definitions of distress, questionable accuracy and an unknown relationship to patient preferences for support care or follow-up. The current study sought to address each of these barriers through the development of the Distress Screening System and evaluation of whether broadening the conceptualization of distress and utilization of advanced psychometrics could improve accuracy and clinical utilities.

The DSS possessed psychometric validity, with the majority of items functioning well within both a traditional psychometric framework and item response theory. The broadened conceptualization of distress and modern psychometrics employed in the current study enabled the DSS to be evaluated against validated paper and pencil screening tools in predicting quality of life and desire for referral. Whereas the DSS did not significantly enhance prediction of either outcome measures, the current study provided greater theoretical and conceptual basis for a broadened definition of patient
distress in cancer care, the utility of advanced psychometrics in screening, and a basis for further exploration.
Figure A.1. Unidimensional, bi-factor three-dimensional and bi-factor seven-dimensional models of distress
**Preliminary analysis of the Distress Screening System**

Goal: Confirm items in the DSS form cohesive factors as hypothesized and demonstrate adequate validity and reliability.

<table>
<thead>
<tr>
<th>Examine item correlations and factor loadings</th>
<th>Examine missing data</th>
<th>Examine convergent and discriminant validity</th>
<th>Examine internal reliability</th>
</tr>
</thead>
</table>

**Model evaluation**

Goal: Determine if the unidimensional, two-dimensional or six-dimensional model of distress provides the most appropriate fit

<table>
<thead>
<tr>
<th>Examine model fit indices</th>
<th>Significant test of chi-square differences</th>
<th>Examine variance portioning</th>
</tr>
</thead>
</table>

**Parameter estimation**

Goal: Utilize advanced psychometrics (IRT) to estimate model parameters and further evaluate model fit

<table>
<thead>
<tr>
<th>Estimate item parameters</th>
<th>Use item parameters to estimate residuals associated with model fit</th>
<th>Examine residuals at category, item and scale level and model fit indices</th>
</tr>
</thead>
</table>

**Evaluate predictive capacity**

Goal: Examine the predictive capacity of the DSS against widely-used distress screening measures

Examine receiver operator curves and area under curve analysis of measures predicting patient quality of life and desire for a referral

Figure A.2. Summary of proposed analysis
Figure A.3. Standardized residuals of the Distress Screening System
Figure A.4. Item demonstrating high discrimination and appropriate range of difficulty (“felt that medical staff care about my well-being”)(a=2.03/ b=0.07,0.98, 1.68, 2.25)
Figure A.5. Item with poor discrimination and inappropriate range of difficulty ("spent time thinking of ways to cope with my illness") (a=.21 / b=-6.85, -1.51, 4.58, 10.43)
Figure A.6. Information curve for the Distress Screening System
Figure A.7. Receiver Operator Characteristic curves for the prediction of quality of life by the Distress Screening System, Hospital Anxiety and Depression Scale and Distress Thermometer.
Figure A.8. Receiver Operator Characteristic curves for the prediction of referral request by the Distress Screening System, Hospital Anxiety and Depression Scale and Distress Thermometer.
APPENDIX B

TABLES
TABLE B.1
SUMMARY OF DEMOGRAPHIC AND HEALTH INFORMATION

<table>
<thead>
<tr>
<th>Gender</th>
<th>Cancer Diagnosis</th>
<th>Time Since Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>28.7</td>
<td>Breast 48.9</td>
</tr>
<tr>
<td>Female</td>
<td>71.3</td>
<td>Prostate 10.2</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>Colon/Rectum 5.0</td>
</tr>
<tr>
<td>Range</td>
<td>20-89</td>
<td>Non-Hodgkin’s Lymphoma 4.5</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>61.41 (12.92)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>68.6</td>
<td>0 - 2 years 19.7</td>
</tr>
<tr>
<td>African American</td>
<td>20.7</td>
<td>3 – 8 Years 44.3</td>
</tr>
<tr>
<td>Religious Preference</td>
<td>Median 6.0</td>
<td>More than 8 Years 36.0</td>
</tr>
<tr>
<td>Christian Faith</td>
<td>Treatment Type*</td>
<td></td>
</tr>
<tr>
<td>Annual Income</td>
<td>Chemotherapy 64.3</td>
<td></td>
</tr>
<tr>
<td>$0- $14,999</td>
<td>16.8</td>
<td></td>
</tr>
<tr>
<td>$15,000 – $24,999</td>
<td>13.5</td>
<td></td>
</tr>
<tr>
<td>$25,000-$49,999</td>
<td>29.5</td>
<td></td>
</tr>
<tr>
<td>$50,000 - $70,000</td>
<td>22.5</td>
<td></td>
</tr>
<tr>
<td>Over $70,000</td>
<td>17.7</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>59.3</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>15.4</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed High School</td>
<td>64.8</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>34.5</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>45.8</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>14.2</td>
<td></td>
</tr>
</tbody>
</table>

Note: This table presents the highest percentage entries. A complete list of all categories is available from the authors. *Patients may have undergone more than one treatment modality.
### TABLE B.2

**DESCRIPTIVE STATISTICS OF THE DISTRESS SCREENING SYSTEM (N=492)**

<table>
<thead>
<tr>
<th>Distress Scale</th>
<th>Range</th>
<th>Mean* (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional State</td>
<td>11-49</td>
<td>23.8 (8.54)</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>12-48</td>
<td>26.5 (6.02)</td>
</tr>
<tr>
<td>Satisfaction with Care</td>
<td>10-41</td>
<td>17.9 (6.97)</td>
</tr>
<tr>
<td>Social Support</td>
<td>11-54</td>
<td>23.0 (8.06)</td>
</tr>
<tr>
<td>Functional State</td>
<td>8-35</td>
<td>15.9 (5.87)</td>
</tr>
<tr>
<td>Total Scale</td>
<td>54-195</td>
<td>107.2 (28.99)</td>
</tr>
</tbody>
</table>

* Higher scores reflect higher levels of distress

### TABLE B.3

**CORRELATIONS BETWEEN DISTRESS SCREENING SYSTEM DOMAINS AND TOTAL SCORE (N=492)**

<table>
<thead>
<tr>
<th>Distress Scale</th>
<th>Emotional State</th>
<th>Self-Efficacy</th>
<th>Satisfaction with Care</th>
<th>Social Support</th>
<th>Function State</th>
<th>Total Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional State</td>
<td>-.</td>
<td>.56**</td>
<td>.52**</td>
<td>.64**</td>
<td>.70**</td>
<td>.86**</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>-</td>
<td>.49**</td>
<td>-.</td>
<td>.57**</td>
<td>.51**</td>
<td>.75**</td>
</tr>
<tr>
<td>Satisfaction w. Care</td>
<td>-</td>
<td>-</td>
<td>.68**</td>
<td>-.</td>
<td>.54**</td>
<td>.80**</td>
</tr>
<tr>
<td>Social Support</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.54**</td>
<td>-.</td>
<td>.86**</td>
</tr>
<tr>
<td>Functional State</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.79**</td>
<td></td>
</tr>
<tr>
<td>Total Scale</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** p < .01
TABLE B.4

CORRELATIONS BETWEEN THE DISTRESS SCREENING SYSTEM AND VALIDATED MEASURES (N=332)

<table>
<thead>
<tr>
<th>Validated Measure</th>
<th>Distress Screening System (Total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression (CES-D)</td>
<td>.68*</td>
</tr>
<tr>
<td>Depression and Anxiety (HADS)</td>
<td>.66*</td>
</tr>
<tr>
<td>Quality of Life (FACT)</td>
<td>-.67*</td>
</tr>
<tr>
<td>Adjustment (PSS)</td>
<td>-.60*</td>
</tr>
<tr>
<td>Distress (DT)</td>
<td>.49*</td>
</tr>
</tbody>
</table>

* = p<.01
## TABLE B.5

DISCRIMINATION ($\alpha$) AND DIFFICULTY ($\beta$) PARAMETERS FOR THE DISTRESS SCREENING SYSTEM

<table>
<thead>
<tr>
<th>Item</th>
<th>Discrimination ($\alpha$)</th>
<th>Difficulty ($\beta_1$)</th>
<th>Difficulty ($\beta_2$)</th>
<th>Difficulty ($\beta_3$)</th>
<th>Difficulty ($\beta_4$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.19</td>
<td>-1.46</td>
<td>0.06</td>
<td>1.67</td>
<td>3.3</td>
</tr>
<tr>
<td>2</td>
<td>1.03</td>
<td>-0.76</td>
<td>0.27</td>
<td>1.46</td>
<td>2.42</td>
</tr>
<tr>
<td>3</td>
<td>1.1</td>
<td>0.2</td>
<td>1.79</td>
<td>3.08</td>
<td>3.44</td>
</tr>
<tr>
<td>4</td>
<td>1.48</td>
<td>-0.05</td>
<td>1.14</td>
<td>2.32</td>
<td>2.86</td>
</tr>
<tr>
<td>5</td>
<td>1.56</td>
<td>-0.41</td>
<td>0.47</td>
<td>1.19</td>
<td>1.93</td>
</tr>
<tr>
<td>6</td>
<td>2.07</td>
<td>-0.96</td>
<td>0.03</td>
<td>0.75</td>
<td>1.18</td>
</tr>
<tr>
<td>7</td>
<td>1.03</td>
<td>1.01</td>
<td>2.11</td>
<td>3.24</td>
<td>3.79</td>
</tr>
<tr>
<td>8</td>
<td>2.03</td>
<td>0.07</td>
<td>0.98</td>
<td>1.68</td>
<td>2.25</td>
</tr>
<tr>
<td>9</td>
<td>0.21</td>
<td>-6.85</td>
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<td>9. spent time thinking of ways to cope with my illness (C)</td>
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* p<.05  
** p<.001  
+ Number of residuals beyond two standard errors  
^ DSS Total / DSS Domain
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<td>Distress Thermometer</td>
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REFERENCES


