

**Distress during Cancer Treatment and its Relation to Posttraumatic Stress
Symptoms:**

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Degree
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ABSTRACT

This dissertation focuses on the psychological response to stress in cancer patients. Specifically, it examines the factors which increase the likelihood of experiencing distress and posttraumatic stress (PTSS), as well as the relationship between distress and PTSS. The dissertation is composed of three manuscripts, the first of which presents a review of the current literature on distress and PTSS in adult cancer patient populations. It indicates that distress is prevalent in cancer patient populations, and that increased levels of distress may be related to PTSS. Furthermore, risk and protective factors are identified, including older age and social support, which may serve as buffers for distress.

The second paper examines a sample of more than 1,100 cancer patients, across more than a dozen treatment centers. Hierarchical linear modeling techniques are used to examine how clinic-level factors might be related to individual distress levels. The third and final paper describes a conditional process model with distress levels as the predictor and PTSS as the outcome, where physical cancer symptoms mediate the relationship between the two and social support and age serve as moderators. Findings from this dissertation have potential implications for both future research and direct practice, within oncology settings. The studies serve as important next steps in a growing body of research.

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INTRODUCTION

Cancer is the second leading cause of death in the United States. Lifetime prevalence rates of cancer in the US are 41 percent for men and 38 percent of women (American Cancer Society, 2017). In addition to the potentially dire health outcomes associated with cancer, patients often experience severe mental health concerns. Psychological distress and posttraumatic stress symptoms are two of the most commonly-experienced problems, with prevalence rates ranging from 30 to 70% and 10 to 17%, respectively (Andrykowski, Cordova, Studts, & Miller, 1998; Bultz & Carlson, 2005; Cordova et al., 2007; Graves et al., 2007; Hegel et al., 2006; Henselmans et al., 2010; Vin-Raviv et al., 2013).

Distress is a term used to describe a combination of symptoms, ranging from depression to anxiety and panic, which are experienced as a result of the stress associated with cancer diagnosis and treatment (Holland et al., 2013). Since the early 2000s, cancer researchers and clinicians have increasingly focused on understanding distress and how it relates to outcomes for cancer patients. To that end, all American College of Surgeon's Commission on Cancer-accredited Cancer Centers are required to conduct distress screening as part of routine care for cancer patients. Moreover, distress is now considered the fifth vital sign in the treatment of cancer patients (Bultz & Johansen, 2011; Carlson et al., 2004).

While a relatively small percentage of cancer patients are diagnosed with full, DSM-defined posttraumatic stress disorder (PTSD), it is much more common for patients to experience partial posttraumatic stress symptoms (PTSS) (Cordova et al., 2007). The most commonly—reported PTSD symptoms among cancer patients are those related to avoidance and intrusive re-experiencing (Kangas, Henry, & Bryant, 2002; Varela, Ng, Mauch, & Recklitis, 2013). As is

with the case with distress, PTSS has been linked to poorer outcomes in both mental and physical health (Palesh & Koopman, 2013).

This dissertation addressed the relationships between distress and PTSS, as well as the relationship between the symptoms of distress and characteristics of the center in which cancer patients were receiving treatment. Data for the dissertation were provided by Tridium, Inc. and were collected at cancer centers across the country, through the company's MHADRO behavioral health assessment and referral system. The sample included data from 1,150 cancer patients, compiled from 19 cancer centers within the continental United States.

This dissertation is divided into three chapters and ends with a conclusion section. The first chapter is a review of the current literature on distress and posttraumatic stress in cancer patients. It serves as background information, and to inform subsequent chapters. Additionally, it highlights the need to better understand the link between distress and PTSS, as well as the contextual factors related to each. The second chapter is an examination of patient and treatment center-level characteristics and their relationships to the presentation of distress symptoms in cancer patients. The third paper uses a condition process model to assess the relationship between distress and PTSS as mediated by cancer symptoms, and moderated by age and levels of social support. The conclusion summarizes information in the earlier chapters, and provides specific implications for policy and practice.

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CHAPTER I
RESPONSE TO STRESS IN CANCER PATIENTS

This manuscript (Chapter 1) has not been submitted for publication and will not be published prior to submission of the final version. Reviews and subsequent revisions were conducted in consultation with my dissertation committee. Reviewers included my dissertation committee: Drs. Matthew T. Theriot (Chair), Cindy Davis, William Nugent, Mary Held, and Russell Zaretzki. I was the sole-author on this original manuscript. My current plan is to submit this manuscript for publication in *Health and Social Work*, once approved by the aforementioned committee.

Abstract

A review of the current literature on distress and posttraumatic stress symptoms (PTSS) within cancer patient populations was conducted to determine which factors serve as risk or protective influences. Further, the research was analyzed in an effort to understand which measurement procedures are used within clinical oncology settings and how those procedures might be improved by a better understanding of distress and PTSS. Upon review of the literature, it was made clear that distress and posttraumatic stress represent separate, but related constructs. Additionally, posttraumatic growth (PTGI) was identified as a related concept.

Introduction

Cancer diagnosis and treatment is a stressful process, with effects that some have compared to those seen in individuals who have experienced active combat exposure (Davis, Sloan, & Tang, 2011; Smith, Redd, Peyser, & Vogl, 1999). In response to these stressors, cancer patients and their families frequently contend with severe distress, as well as acute or posttraumatic stress disorder (PTSD), or partial posttraumatic stress symptoms (PTSS) (Varela, Ng, Mauch, & Recklitis, 2013). Not surprisingly, cancer patients have been found to experience symptoms of PTSD at rates significantly higher than those found within the general public (Pujol et al., 2013; Vin-Raviv et al., 2013). Cancer-related distress may not abate without appropriate psychological treatment (Carlson, Groff, Maciejewski, & Bultz, 2010). Untreated chronic distress, PTSS, and PTSD are also frequently linked to increased risk for other mental health problems, the onset of health concerns such as cardiovascular disease, and premature death (Boscarino, 2004). Although cancer diagnosis and treatment can rightfully cause stress for patients, the stress can result in positive change. This positive change has been termed “posttraumatic growth” (PTG) (Tedeschi & Calhoun, 1996).

The American College of Surgeons’ Commission on Cancer (CoC) recently mandated that accredited cancer centers implement some method of monitoring distress in their patients by 2015. With 1,688,780 projected new cancer diagnoses in 2017, addressing psychosocial needs in oncology is of paramount importance (American Cancer Society, 2017; Siegel, Miller, & Jemal, 2016). Understanding the role of PTG, PTSD, and PTSS, along with their relationship to the stress resulting from cancer is critical to improving patient care and outcomes (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Kwekkeboom & Seng, 2002).

Search Protocol

Searches were conducted in Google Scholar, PsychInfo, Medline, and PubMed. The focus of this search was empirical research published in peer-reviewed journals and literature from 2002 to 2017 was included, along with some earlier foundational works. Studies with pediatric or adolescent samples were excluded. Searches were conducted, using combinations of terms from the following list: *stress, distress, traumatic stress, posttraumatic, post-traumatic, PTSD, PTSS, PTS, cancer, oncology, carcinoma, leukemia, lymphoma, PTG, posttraumatic growth, post-traumatic growth, *traumatic growth, and distress thermometer.

Distress

Defined

Understandably a stressful process, cancer diagnosis and treatment can cause clinical levels of psychological distress. Distress has been recognized as the “sixth vital sign” in cancer care (Bultz & Johansen, 2011; Holland & Bultz, 2007). Researchers have compared this recognition to the inclusion of pain as the “fifth vital sign” (Carlson et al., 2004).

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (Holland et al., 2013, p. 192)

The term “distress” was selected and described as preferable to the traditional mental health labels and the stigma that accompany them and was purposefully chosen for this reason (Holland & Alici, 2010; Mitchell, 2013).

Prevalence

Prevalence rates for psychological distress in cancer patients are regularly reported between 30% and 70% (Bultz & Carlson, 2005; Graves et al., 2007; Hegel et al., 2006; Henselmans et al., 2010; Hollingworth et al., 2013). Though there is significant variation in these rates, large-scale studies of cancer patients have found significant distress levels present in 32% or more of patients (Carlson et al., 2004; Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013; Grassi et al., 2013; Kendall, Glaze, Oakland, Hansen, & Parry, 2011; Singer et al., 2012; Zabora, Brintzenhofescho, Curbow, Hooker, & Piantadosi, 2001). Furthermore, it is estimated that almost one-third of all cancer patients will experience severe levels of distress, and 15% or more may experience chronic distress (Carlson & Bultz, 2003; Carlson et al., 2013; Clark et al., 2012; Henselmans et al., 2010).

Screening

As emphasized by the CoC mandate, early detection of distress is important. Henselmans et al. (2010) found that most of the women who experienced distress during breast cancer treatment were distressed during the early stages. The most commonly used distress measure is the NCCN Distress Thermometer (DT), a single, self-report measure with an associated 39-item “problem list”. It has become popular in part due to its brevity, adaptability, and ease of use, and has been widely studied (Jacobsen, 2007). With a suggested cut score of 4 or more, the DT has shown reasonable sensitivity and specificity, though adding additional measures, such as the Impact Thermometer (IT), has improved the results (Akizuki, Yamawaki, Akechi, Nakano, &

Uchitomi, 2005; Jacobsen & Ransom, 2007; Lynch, Goodhart, Saunders, & O'Connor, 2010; Mitchell, 2010; Ransom, Jacobsen, & Booth-Jones, 2006; Rohan, 2012). Furthermore, older patients with poorer vision may need help completing the self-report measure (Hurria et al., 2009). Despite its limitations, the benefits of the DT's flexibility and cost savings make it a preferred option for distress screening, and it has shown the ability to distinguish emotional distress from physical distress in cancer patient populations (Steinberg et al., 2009)

The Hospital Anxiety and Depression Scale (HADS), Patient Health Questionnaire-9, and the Brief Symptom Inventory-18 (BSI-18) have been frequently utilized in both research and practice, but the use of these scales in routine care is limited, due to the costs associated with their utilization (Mehnert, Lehmann, Graefen, Huland, & Koch, 2010; Rohan, 2012). Research has found that the DT performs comparably to the HADS, PHQ-9 and BSI-18 in identifying patients with psychological distress (Gessler et al., 2008; Grassi et al., 2013; Hegel et al., 2008; Jacobsen et al., 2005).

Praise for the DT has focused largely on its ease of use and feasibility in clinical practice (Carlson et al., 2010; Grassi et al., 2013; Lynch et al., 2010). The ease of implementation and the minimization of costs associated with the DT means less burden on the patient, which is important during the already stressful time of diagnosis and treatment (Schneider et al., 2010)

Risk and Protective Factors for Distress

Distress risk may vary by cancer type, with those experiencing lung, brain, or head and neck cancers reporting higher levels (Brocken et al., 2015; Carlson et al., 2004; Graves et al., 2007; Zabora et al., 2001). Rates were also higher for depressed patients, and may be highest shortly after diagnosis (Andreu et al., 2012; Hegel et al., 2008).

Demographic variables have inconsistently been shown to predict distress levels. For example, race and education have often been unrelated to distress (Davis et al., 2011; Graves et al., 2007). Andreu et al. (2012) found that, in a sample of breast cancer patients measured at multiple time points, there was no relationship between distress levels and age, marital status, education level, or employment status. In a study by Carlson et al. (2004), minority patients and those with lower reported income were more likely to report significant distress. Despite these discrepancies, much of the research over the past 15 years has reported that younger patients were more likely to report high levels of distress (Graves et al., 2007; Kaiser, Hartoonian, & Owen, 2010; Schnoll & Harlow, 2001; van Scheppingen et al., 2011; Zabora et al., 2001). Physical health symptoms have also been frequently reported as potential risk factors for distress (Clark, Rochon, Brethwaite, & Edmiston, 2011; Grassi et al., 2013; Graves et al., 2007).

Relational variables may offer some insight into the development of distress and serve as possible protective factors. Studies have found that the quality of mother/child relationships and perceived social support led to decreases in psychological distress (Andreu et al., 2012; Cordova et al., 2007; Davis et al., 2011; Singer et al., 2012). Based on their findings related to the association between intimate partner social support and distress levels, Manne, Badr, Zaider, Nelson, and Kissane (2010) suggested that future interventions address patient-partner intimacy in an effort to improve distress resistance.

Posttraumatic Stress

Defined

Traumatic stress includes the DSM-defined posttraumatic stress disorder (PTSD), as well as sub-clinical PTSD symptoms – also known as posttraumatic stress symptoms (PTSS). Traumatic stress disorders are defined by the Diagnostic and Statistical Manual of Mental

Disorders, Fifth Edition (DSM-5) as exposure to the traumatic event, accompanied by four symptom clusters: intrusive re-experiencing, avoidance, negative mood or cognitions, and arousal or reactivity alterations (American Psychiatric Association, 2013). While not meeting the full diagnostic criteria for PTSD, PTSS can significantly impact functioning. Posttraumatic stress is frequently linked to numerous adverse outcomes, both psychological and physical (Palesh & Koopman, 2013). The most commonly reported symptoms of posttraumatic stress in cancer patients are those of intrusive re-experiencing and avoidance, though avoidance symptoms may be less likely in lung cancer patients (Cordova et al., 2007; Kangas, Henry, & Bryant, 2002; Pujol et al., 2013; Varela et al., 2013)

Prevalence

Although identifying prevalence rates of PTSS and PTSD are difficult and the source of some controversy, Andrykowski, Cordova, Studts, and Miller (1998) cited the most commonly reported cancer-related PTSD rates as being between 10 and 15%. Similarly, Cordova et al. (2007) found that 11% of breast cancer patients surveyed met the clinical criteria for PTSD, while 17% demonstrated partial PTSD symptoms. Twenty-three percent of recently-diagnosed breast cancer patients reported symptoms of posttraumatic stress (Vin-Raviv et al., 2013).

Screening

Although most centers have begun distress screening, there are no current specific screening requirements for acute or posttraumatic stress. This means that the identification of acute stress disorder (ASD), PTSD, or PTSS may only occur if the patient meets the required cut score on the Distress Thermometer, and is referred for additional treatment. Effective methods for identifying traumatic stress exist, however the associated costs and patient participation often make additional or intensive assessment unrealistic (Fielding & Lamb, 2013; Jacobsen, et al,

2005). Therefore, the challenge is one of adapting current screening methods so that they are more robust, but do not require significant additional resource investment. Some have suggested that the NCCN guidelines for the assessment of distress should be used when considering how to identify and treat cancer patients who may be experiencing symptoms of posttraumatic stress (Holland et al., 2013; Palesh et al., 2013)

A number of PTSD measures are used in oncology research, however none are universally-used in day-to-day practice. One of these measures, the PTSD Checklist – Civilian Version (PCL-C) appears frequently and has determined to be effective in identifying PTSD in cancer research (Andrykowski et al., 1998; Black & White, 2005; Cordova et al., 2007; Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000; DuHamel et al., 2004; Mehnert et al., 2010; Salsman, Segerstrom, Brechting, Carlson, & Andrykowski, 2009; Shelby, Golden-Kreutz, & Andersen, 2005). While the PCL-C is more frequently used, initial research has shown the potential utility for short-form screening instruments like the PC-PSTD in oncology settings (Hegel et al., 2006). The gold standard for the identification of PTSD – clinician interviews – are less commonly used due to limited time and resources, but have been shown to produce lower rates of PTSD diagnoses (Swartzman, Booth, Munro, & Sani, 2017).

Risk and Protective Factors for Posttraumatic Stress

Studies have frequently found younger age to be a risk factor for PTSS and PTSD (Rourke, Hobbie, Schwartz, & Kazak, 2007; Swartzman et al., 2017; Vin-Raviv et al., 2013). Similarly, those diagnosed before age 50 were more likely to experience PTSD (Vin-Raviv et al., 2013). African-American breast cancer patients were more likely than their white counterparts to report symptoms of PTSD (Vin-Raviv et al., 2013). Other possible predictors of PTSD

include low socioeconomic status, previous trauma, and a history of other psychological problems (Cordova, Riba, & Spiegel, 2017; Vin-Raviv et al., 2013).

Additionally, some research has indicated cancer type may moderate the incidence of PTSD. For example, those undergoing treatment for prostate cancer may experience lower levels of PTSD than women undergoing treatment for breast cancer (Mehnert et al., 2010; Swartzman et al., 2017). Treatment type may also alter PTSD likelihood, as prolonged treatments such as chemotherapy have been related to increased prevalence (Swartzman et al., 2017).

High levels of distress have also been associated with PTSD (Pujol et al., 2013). In a meta-analysis of 110 cancer-related PTSD studies, Swartzman et al. (2017) found that PTSD rates varied by geographic region. Specifically, the proportion of samples reporting PTSD was the highest in studies conducted in the Middle East. Studies conducted in the U.S. reported PTSD less frequently, but at four times the rate of studies from Asia. The effects of posttraumatic stress have also been shown to extend beyond those diagnosed. PTSD has presented in not only cancer patients, but in their partners as well (Manne et al., 2004).

Posttraumatic Growth

Defined

Posttraumatic growth (PTG) is a framework often utilized to understand why some cancer survivors (OR those with traumatic health experiences) experience more positive change. The PTG model suggests that positive change can occur in response to a traumatic event that disrupts an individual's belief about the world and through the process of rebuilding those beliefs, growth known as PTG can occur. Overall, this model posits that the catalyst for growth is the perceived threat of the event. A diagnosis of cancer can be viewed as an event that

potentially disrupts an individual's life, but can lead to PTG (Tedeschi & Calhoun, 2004). PTG has been shown to be related to improved quality of life (Lelorain, Bonnaud-Antignac, & Florin, 2010). The effects of PTG can last years beyond the cancer experience (Cordova et al., 2001; Lelorain et al., 2010)

Prevalence

Rates of PTG in excess of 80% are frequently reported in cancer patients and survivors (Sears, Stanton, & Danoff-Burg, 2003; Sumalla, Ochoa, & Blanco, 2009; T. Weiss, 2004). PTG can occur early during cancer treatment. Danhauer et al. (2013) reported that increased PTG occurred primarily in the first few months following the diagnosis of breast cancer.

Screening

The Posttraumatic Growth Inventory (PTGI) is a 21 item self-report measure, the scores of which represent five domains (relating to others, new possibilities, personal strength, spiritual change, and appreciation of life) of positive personal growth (Tedeschi et al., 1996). The PTGI is frequently used throughout the literature on psychosocial oncology, and has shown to produce good reliability and validity in cancer populations (Danhauer et al., 2013; Manne et al., 2004; Morrill et al., 2008; Salsman et al., 2009; Scrignaro, Barni, & Magrin, 2011; Silva, Moreira, & Canavarro, 2012; T. Weiss, 2004)

Risk and Protective Factors for Posttraumatic Growth

The most frequently identified factors related to variance in PTG are age, gender, and social support. Younger age has been linked to increased levels of PTG, particularly in breast cancer patients (Cordova et al., 2007). PTG is more frequently reported in female cancer patients than in male patients (Bellizzi, 2004). This relationship is unclear, however, and may be a result of the disproportionate number of breast cancer patients represented in cancer research.

PTG may even extend to the loved ones of cancer patients. Research conducted by Weiss (2004) indicated that husbands of recent breast cancer survivors experienced elevated levels of PTG and that the wife's level of PTG significantly predicted levels in their partner. Emotional support may increase PTG (Schroevers, Helgeson, Sanderman, & Ranchor, 2010)

The Interconnected Nature of Distress, Posttraumatic Stress and Posttraumatic Growth

Distress, PTSD/PTSS, and PTG, although distinct constructs, are frequently found to be related. Higher levels of stress may also be related to high levels of PTG in cancer patients (Thornton & Perez, 2006). Other research demonstrates that PTG works as a protective factor for stress during cancer treatment (Silva et al., 2012). Cordova et al. (2001) found that PTG occurred independent of distress and suggested that PTG "is possible and might be facilitated through cognitive-emotional processing and confrontation of loss and threat" (p. 182). PTG has also been shown to decrease depressive symptoms and improve quality of life in cancer patients with PTSS (Morrill et al., 2008).

Park, Chmielewski, and Blank (2010) reported a link between PTG and the posttraumatic symptoms of intrusion and adjustment. They, therefore, posited that PTG may serve as a moderating influence on the development of posttraumatic stress symptoms (Park et al., 2010). The relationship between PTG and partial PTSS was reported in subsequent studies as well (Danhauer et al., 2013). Cordova et al. (2007) found no relationship between scores on the PCL-C and PTGI. Similarly, other research has found no direct causal relationship between full PTSD and PTG, meaning that the pathways by which patients arrive at these outcomes may be different (Chan, Ho, Tedeschi, & Leung, 2011; Salsman et al., 2009).

Tzipi Weiss (2004) found that supportive relationships were related to higher levels of PTG. Similarly, social support may increase levels of PTG (Danhauer et al., 2013; Scrignaro et

al., 2011). Given this, it appears that social support may act as a moderator for PTG, distress, and potentially PTSS and PTSD.

Significance and Future Directions

PTSD and traumatic stress symptoms are often persistent and can result in poor mental and physical health outcomes, health risk behaviors (e.g. smoking), and decreased healthcare utilization (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Palesh et al., 2013). PTSD has also been consistently associated with cardiovascular disease, and it has been suggested that PTSD may predispose patients to autoimmune disorders (Boscarino, 2004). Each of these factors contributes to the relationship between PTSD and increased premature death, and is frequently associated with chronic PTSD symptoms.

Research indicates that the most effective way to identify traumatic stress in cancer patients is to conduct multidimensional assessments at different times and in different ways (Poder, Ljungman, & von Essen, 2008; Smith et al., 1999). Unfortunately, conducting assessments in that way can be very costly and time consuming, and simply not practical in many clinics. Not surprisingly, the clinics that are not able to outlay the resources needed are often those that treat the underserved. In light of this reality, it is important to identify those most at risk and to improve screening procedures so that they are more efficient and maximize available resources.

Limitations of the current research on PTSD among cancer patients include a lack of generalizability and understanding of risk factors among diverse populations, with diverse diagnoses. A large portion of the PTSD literature in oncology focuses on breast cancer survivors. While this population consistently exhibits high levels of traumatic stress and is certainly worthy of study, the focus on this population limits the ability to generalize results to

men and to those with other types of cancer (Varela et al., 2013). Additionally, the distinct differences in type and severity of diagnosis and treatment can complicate generalizability. For example, stress factors for lung cancer have been shown to be different than other types of cancer given a possible perception of responsibility for illness (Pujol et al., 2013). There has also been limited research produced with regard to PTSD – as defined by the DSM-5 – with cancer patients (Cordova et al., 2017). Understanding the relationship between the new criteria for posttraumatic stress and cancer of all types is an important future step.

Although distress screening has been mandated in many cancer centers, no specific requirements exist for traumatic stress evaluation. Balder and De-Nour (1997) previously found a relationship between distress as measured by the brief symptom inventory (BSI) and intrusive PTSD symptoms. Not enough is known about the usefulness of the Distress Thermometer in similarly identifying diagnostic domains of traumatic stress. Given the importance of proper evaluation and the limited resources available to many clinics, additional utility of this existing instrument would be ideal. Using a cut score of 7, the DT identified depression in a sample of newly diagnosed breast cancer patients (Hegel et al., 2008). Furthermore, Akizuki et al. (2005) found that using the IT in conjunction with the DT proved effective in identifying cancer patients with adjustment and major depressive disorders. This may indicate that the DT possesses utility for identifying cancer patients with other depressive or anxiety-related disorders.

Not enough is known about how treatment setting or location may impact distress, PTSS/PTSD, and PTG. Oktay, Nedjat-Haiem, Davis, and Kern (2012) suggested that identifying whether or not treatment setting is related to untreated distress is an important step in identifying differences that may exist between rural cancer centers, private practices, hospitals, and large cancer centers (p. 664). In other research, the physician-patient relationship was related to

patient distress levels, where greater perceived physician attentiveness and empathy resulted in lower levels of distress (Zachariae et al., 2003).

Future research should further explore the cognitive processing mechanism and to what degree social support aids in processing the cancer experience (Morris & Shakespeare-Finch, 2001). The role of social support is clearly important to cancer patients before, during, and after treatment, and understanding how it alters mental health outcomes is needed in order to better harness the positive effects. Ultimately, it has been suggested that interventions should be focused on developing and enhancing PTG in cancer patients, as a mechanism to improve adjustment following treatment (Silva et al., 2012).

Conclusion

The psychological toll of a serious illness like cancer can severely disrupt one's mental well-being. Social workers have been charged with meeting the psychosocial needs of cancer patients since the 1940s, and in today's health care system, are often the primary point of contact for psychosocial assessment, referral, and sometimes treatment (Rohan, 2012). Cancer patients often experience distress, anxiety, depression, and other mental health concerns. Additionally, stress has been shown to result in negative physical health outcomes, such as immune response impairment (Reiche, Nunes, & Morimoto, 2004). Further complicating the issue is that many organizations are unable to increase resource availability to meet patient needs, leading to limitations on their ability to provide adequate assessment and treatment (Schofield, Carey, Bonevski, & Sanson-Fisher, 2006). This is a particular problem in smaller centers, hospitals and other facilities, which often lack the resources of large cancer centers, but collectively see the majority of patients. Research has shown that early identification and treatment of the psychological symptoms associated with cancer greatly reduces the recovery period (Brocken et

al., 2015). Though the costs associated with screening and evaluation are often a primary concern in implementing new systems, it is important to remember the potential savings through reduced medical costs (Carlson et al., 2003).

Distress screening has emerged as a critical topic for oncology social workers, particularly given the 2012 American College of Surgeons' CoC guidelines. One of the challenges presented to the profession is effectively and efficiently identifying cancer patients who are manifesting clinical distress. Additionally, clinicians must have an effective method for identifying patients whose symptoms go beyond distress and may indicate potential posttraumatic or acute stress disorders. An improved understanding of the factors that predispose individuals to distress and traumatic stress will allow clinicians to better identify those patients who are more likely to experience problems, and therefore provide a higher quality of care. This will help social workers better anticipate patient needs and to more efficiently connect them with needed resources. Streamlining distress detection and care is critical, particularly in small or rural cancer centers, which may be lacking in resource availability. Effective early screening for distress and traumatic stress is an important step in the assessment of potential psychological factors during cancer care. Effective implementation of screening processes and psychological care can help improve patient outcomes, aid in the maximization of resources, encourage treatment adherence, improve patients' physical health, and reduce overall healthcare costs (Andersen et al., 2007; Graves et al., 2007; Hurria et al., 2009; Rohan, 2012; Wade, Nehmy, & Koczwara, 2005; Zabora et al., 2001). While not all patients will require psychological or pharmacological support, it is critical that all are assessed in a timely manner and offered services as needed (Davis, 2004).

Once patients with severe distress or symptoms of traumatic stress are identified, clinicians will be better equipped to direct patients to appropriate sources for treatment, and improve long-term health outcomes. Research suggests that efficacious interventions for cancer patients experiencing severe distress or traumatic stress, as well as the importance of beginning these treatments as early as possible (Bryant, 2003; Chan et al., 2011; Faller et al., 2013; Holland et al., 2010; Jacobsen et al., 2007; Lockett, Britton, Clover, & Rankin, 2011; Speca, Carlson, Goodey, & Angen, 2000). This means that the identification of symptoms is critical. Additionally, interventions may promote the development of PTG and understanding the factors related to PTG can aid clinicians in addressing deficits which may function as barriers to recovery (Barskova & Oesterreich, 2009; Chan et al., 2011).

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CHAPTER II
A MULTILEVEL ANALYSIS OF ELECTRONICALLY-REPORTED
DISTRESS LEVELS

This manuscript (Chapter 2) has not been submitted for publication and will not be published prior to submission of the final version. Reviews and subsequent revisions were conducted in consultation with my dissertation committee. Reviewers included my dissertation committee: Drs. Matthew T. Theriot (Chair), Cindy Davis, William Nugent, Mary Held, and Russell Zaretzki. I was the sole-author on this original manuscript. My current plan is to submit this manuscript for publication in *The Journal of Oncology Social Work*, once approved by the aforementioned committee.

Abstract

Introduction: Psychological distress is often seen in patients during cancer diagnosis and treatment. Although the body of literature around cancer-related psychological distress is growing, the possible effect of center-level characteristics has not been assessed. This study sought to examine these effects in a large, heterogeneous sample.

Methods: Distress screening data were collected during intake, as part of a comprehensive behavioral health assessment and referral program at seventeen cancer centers in nine states. A secondary analysis of these data was conducted using hierarchical linear modeling to assess the within and between center effects of individual ($n = 1,112$) and treatment center-level ($n = 17$) characteristics on self-reported levels of individual distress.

Results: The study found that fifteen percent of the variation in individual distress levels could be accounted for by center-level effects. Patient age was found to be inversely-related to distress level, among treatment centers. Additionally, the treatment setting (rural or non-rural) was related to the variation in reported distress levels. Specifically, patients in rural cancer centers were more likely to report lower levels of psychological distress.

Discussion: Understanding predisposing characteristics for distress has direct effects on the care provided by behavioral health personnel. Furthermore, the psychological wellbeing of cancer patients relates directly to long-term outcomes and oftentimes, the ability for physicians to effectively deliver treatment. This study presents some novel findings, in that not only are cancer patients more likely to experience distress due to individual characteristics, but the effect of where they are treated may also have implications on risk and protective factors for developing severe distress.

Introduction

Background

There are expected to be more than 1.6 million new cancer cases diagnosed during 2017, and cancer is currently the second-leading cause of death in the United States (American Cancer Society, 2017). The psychological toll of a serious illness like cancer can be severely disruptive to one's life and result in long-term repercussions for their mental health. Front-line staff such as oncology social workers have been charged with meeting the psychosocial needs of cancer patients since the 1940s, and in today's health care system, are often the primary point of contact for psychosocial assessment, referral, and sometimes treatment (Rohan, 2012).

As part of diagnosis and treatment, cancer patients often experience adverse conditions that result in depression, anxiety, and other mental health concerns. More recently, the term "distress" has been coined to encompass many mental health symptomologies, while doing so in a way that may be less stigmatizing than traditional diagnostic labels. Understandably a stressful process, cancer diagnosis and treatment have been shown to cause significant levels of psychological distress. According to the National Comprehensive Cancer Network (NCCN), distress is comprised of several potential psychological, social, and spiritual symptoms that can manifest in a number of possible negative outcomes (Holland et al., 2013). Distress is frequently observed in cancer patient populations, with prevalence rates regularly reported between 45 and 50% and as high as 70% or more (Bultz & Carlson, 2005). Furthermore, it is estimated that as much as one-third of all cancer patients will experience severe levels of distress (Carlson & Bultz, 2003; Clark et al., 2012).

Understanding, assessing, and treating psychological distress is a critical component of cancer care. Untreated distress can lead to severe mental and physical health outcomes, and

symptoms of severe distress may not improve without treatment (Carlson, Groff, Maciejewski, & Bultz, 2010). Researchers have documented efficacious interventions for cancer patients experiencing severe distress or traumatic stress, as well as the importance of beginning these treatments as early as possible (Bryant, 2003; Chan, Ho, Tedeschi, & Leung, 2011; Faller et al., 2013; Holland & Alici, 2010; Jacobsen & Ransom, 2007; Lockett, Britton, Clover, & Rankin, 2011; Speca, Carlson, Goodey, & Angen, 2000). Therefore, understanding the contextual factors related to distress and improving assessment processes is an important step toward improving psychosocial cancer care.

Purpose

The link between demographic factors and risk for psychological distress has been inconsistently reported within the distress literature. Specifically, education level and ethnicity have often been found to be unrelated to variation in psychological distress (Davis, Sloan, & Tang, 2011; Graves et al., 2007). Despite these inconsistencies, age has been frequently linked to distress. Younger age has often been identified as a risk factor for increased distress, while older age may serve as a protective factor (Graves et al., 2007; Kaiser, Hartoonian, & Owen, 2010; Rourke, Hobbie, Schwartz, & Kazak, 2007; Schnoll & Harlow, 2001; van Scheppingen et al., 2011; Zabora, Brintzenhofeschoc, Curbow, Hooker, & Piantadosi, 2001). Some researchers have found that women are more likely to experience distress (Brocken, Prins, Dekhuijzen, & van der Heijden, 2012).

Further complicating the issue is that many organizations are unable to increase resource availability to meet patient needs, leading to limitations on their ability to provide adequate assessment and treatment (Schofield, Carey, Bonevski, & Sanson-Fisher, 2006). This is a particular problem in smaller centers, hospitals and other facilities, which often lack the

resources of large cancer centers, but collectively see the majority of patients (American Cancer Society, 2011). Researchers have suggested that patient perceptions of the domains related to service delivery and patient-provider relationships within the healthcare treatment setting may be related to better treatment adherence and long-term outcomes (Flocke, Strange, & Zyzanski, 1998). Furthermore, the analysis of healthcare data, as modeled with patients clustered within clinics differing on characteristics such as an urban or rural setting has been advocated (Dickinson, 2005). While not specific to distress, Louis et al. (2017) found significant differences in cancer treatment delivery among rural for-profit treatment centers, when compared to non-profit organizations.

The purpose of the current study was to examine the variance of distress levels within and between treatment centers, and to explore underlying clinic-level factors that may alter the relationship between individual differences and psychological distress. There currently exists a gap in the literature, with regard to the role of treatment setting on individual distress level. As clinical level characteristics such as setting (rural versus suburban or urban) and organizational profit structure have been related to patient-level service delivery, it stands to reason that behavioral health outcomes and organizational factors may share a similar relationship. Despite the lack of research, the role of treatment setting has been recognized as a potentially important factor in understanding the how patients respond to the stress of cancer treatment (Oktay, Nedjat-Haiem, Davis, & Kern, 2012).

To address the purpose of the study, we sought out to answer the following research questions: “What proportion of the variance in distress levels is due to differences among treatment centers?” and “To what degree do mean distress levels vary among treatment centers?”. Furthermore, based upon the literature that indicates an inverse relationship between

age and distress levels, it was hypothesized that distress levels would decrease, as mean age increased. It was also hypothesized that female gender would be associated with increases in mean distress level. The relationship between age and distress, as well as gender and distress was hypothesized to vary among treatment center. Additionally, it was hypothesized that being treated in a rural treatment center would decrease levels of distress, as would being treated in a for-profit center. Finally, it was hypothesized that the effects of age and gender on distress levels would vary based upon treatment center and for-profit/non-profit structure.

Methodology

Data and Sample

A total of 1,147 participants were surveyed at 17 cancer treatment centers within the continental United States. These data were collected during routine intake screening, by way of an electronic assessment and automated behavioral health referral tool. Responses were recorded on an electronic tablet during the patient's initial visit, and screening materials were available in both English and Spanish. Data were collected by the managing digital behavioral health company and de-identified data were provided to the investigators. Institutional review board (IRB) approval was received at the University of Tennessee and a secondary analysis was conducted, with variables identified at both the individual and treatment center-level.

Center-Level Variables

Rural. Treatment centers were located in nine different states and in geographically-diverse areas. Of the 17 centers included in this study, 13 were located in suburban or urban areas, while four were located in rural areas. Binary coding was used for this predictor, with 0 representing non-rural centers and 1 representing rural clinics. Although the number of rural to non-rural clinics was unevenly distributed, the number of patients from the clinics was more

evenly split. Just over 40 percent of the total sample was represented by participants from the rural sites, while 59.6 percent were treated in the non-rural sites.

Non-Profit. Eleven of the centers in this study were identified as non-profit organizations, while the remaining six were for-profit entities. The majority of patients in this study were treated at the non-profit centers, with just 18.3 percent of all participants being treated at the for-profit centers (see Table 2.1). This level-two factor was coded 0/1, with 1 indicating a non-profit center.

Individual-Level Variables

Although several individual-level variables were captured as part of the assessment, only age and gender were available to describe the demographic characteristics of the sample. Several types of cancer were represented in these data, but this information was not captured for more than one third of participants. For this reason, cancer type was not used in the models described in this paper. The level one predictors used were age and gender, while the individual-level outcome variable was distress.

Age. Age for each participants was recorded in years. As shown in Table 2.1, the mean age for participants was 60.76 years ($SD = 12.94$). Patients ranged in age from 18 to 93, with nearly 60 percent of the sample being aged 50 to 69. The distribution of ages were similar in the rural and non-rural centers, as well as the for-profit and non-profit centers.

Gender. A binary response was captured for gender, with patients self-identifying as male or female. The sample was nearly three-fourths female, with only 31.8 percent of respondents identifying as male. The percentage found in rural and non-rural centers was similar, with 32.2 and 31.2 percent male patients, respectively. Likewise, the split among for-

profit and non-profit centers was close to the overall percentage, with 32.4 and 31.7 percent male patients.

Distress. The outcome variable for this study was psychological distress. Respondents were asked to rate their level of psychological distress, using the single-item NCCN Distress Thermometer (DT). The DT is a brief and easy to understand instrument, and is commonly-used in cancer treatment centers (Hegel et al., 2008; Jacobsen, 2007). Scores from zero to ten were recorded, with zero representing no distress and ten representing extreme levels.

INSERT TABLE 2.1 HERE

Data Analysis

Data preparation and additional descriptive procedures were conducted using IBM Statistical Package for the Social Sciences (SPSS), version 24.0. Assumptions were tested and problematic data were addressed prior to analysis. Cases with missing values on the predictor or outcome variables were removed. Listwise deletion was utilized, rather than an imputation method. The distribution of study variables among the deleted cases was analyzed and it was determined that the omitted cases did not differ meaningfully from those in the analyses. Following data cleaning, 1,112 cases remained for analysis.

Additionally, a post-hoc power analysis was conducted, using the technique outlined by Hox (2010), wherein total sample size, cluster-level means, and the intraclass correlation coefficient (ρ) were used to determine an effective sample size. The formula is given as:

$$n_{eff} = n/[1 + (n_{clus} - 1)\rho]$$

The resulting value indicated an effective sample size of 105 for this study. A comparative A-priori power analysis was conducted in G*Power version 3.1.9.2 (Faul, 2007). This analysis

indicated that the effective sample size would have been sufficient to detect a moderate effect size, given an alpha value of .05, and a power of .80 in a linear regression model.

As these data were nested, with cancer patients clustered within cancer centers, two-level hierarchical linear modeling (HLM) was used to evaluate variation in distress levels across treatment centers and to examine the effects of clinic-level characteristics on individual distress scores. This is consistent with other studies, which have used HLM to model clinic-level differences in medical settings (Dickinson & Basu, 2005; Flocke, et al., 1998). HLM, version 7.01 (HLM7) by Raudenbush, Bryk, and Congdon (2013) was used to construct the two level models and Restricted Maximum Likelihood (REML) was selected as the estimation method. According to Hox (2010), REML provides estimates with less bias than Full Maximum Likelihood (FML) estimation and is more accurate when the number of level two groups is small (p. 234). Additional analyses were conducted using FML, but ultimately, both estimation methods resulted in the same model being selected.

Five models were constructed, with each model nested within the subsequent one. The fully unconditional model (Model 1) was constructed to evaluate the variation in distress scores across clinics, without other predictors. This model addressed the first two research questions, relating to the variability of distress levels across patients and among treatment centers. Models 2 and 3 incorporated age and gender as level one predictors, with age centered on the grand mean in these, and all subsequent analyses. The random intercept and fixed slopes model (Model 2) allowed for variance in intercept values across patients, while the random intercept and random slopes model (Model 3) added variation in the age and gender slopes across patients. The hypothesized relationships between individual factors and mean distress levels, and those related to the variability of the effect of age and gender on distress by treatment center were addressed

by models 2 and 3, respectively. Level two variables – rural and non-profit – were added in the random intercept and slopes model (Model 4), where main effects for the level two variables were tested. This model directly addressed the hypothesis that rural clinics and non-profit centers would be related to lower distress levels. The random intercept and slopes as outcomes model (Model 5) was the final combination and was used to examine cross-level interactions between the rural and non-profit variables, along with level-one variables age and gender, on psychological distress. This structure allowed for the examination of variation in level one effects on distress, across treatment centers, with different level two characteristics. Notation for each of the nested models is available in the Appendix B.

Results

Prior to constructing the hierarchical models, distress levels were plotted against centered age in SPSS to visualize the potential variation in the relationship, at the clinic level. Figure 2.1 illustrates this variation, with each line representing the individual treatment center slopes. Data were then loaded into HLM7 to construct the nested models.

INSERT FIGURE 2.1 HERE

The Unconditional Model

Model 1 represents the fully unconditional, or null, model. Here, only the intercept was included, and allowed to vary across treatment centers. Findings indicated a statistically significant variation in the mean of means, or variation in distress scores among centers ($\chi^2(16)=250.12, p<.001$). Further, the intraclass correlation (ICC) value was given as 0.15, meaning that fifteen percent of the variance in distress scores could be accounted for by treatment setting, while 85 percent was due to differences among patients.

Random Intercept and Fixed Slopes Model

The second model included grand-mean-centered AGE and the binary GENDER variable as patient-level factors. Deviance values were reduced with this model, as was the AICc value, indicating that it was a better overall fit than the unconditional model. Increase in client age was associated with a reduction in distress level, when controlling for gender, as each one unit above the centered age resulted in a decrease of 0.02 in DT scores ($b = -.02, p < .001$). Additionally, mean distress levels varied significantly across treatment centers for those at the mean age ($p < .001$). These results supported the hypothesis related to age, but the hypothesized relationship between gender and distress was not supported.

Random Intercept and Random Slopes Model

As with the random intercept and fixed slopes model, model three allowed for variation in the intercept and contained two level-one predictors. In addition, slopes in the regression equation were allowed to vary by treatment center. Again, distress levels varied among centers ($\chi^2(14)=119.35, p < .001$), and increased age was associated with decreases in distress ($b = -.02, p = 0.039$), when controlling for gender. There was, however, no significant influence from the slopes of age ($p = .236$) or gender ($p = .208$) on the variation of distress among treatment centers. The deviance value for this model was lower than in Model 2, but the added parameters resulted in an AICc value indicative of a poorer-fitting model. As with the previous model, the hypothesized relationship between age and distress – as it varied among treatment centers – was supported, while the complimentary hypothesis for gender was not.

Random Intercept and Random Slopes Model, with Level 2 Main Effects

Model 4 included the level one variables from previous models and the addition of level two predictors, with fixed slope coefficients for RURAL and NON-PROFIT. Results indicated

that there was a main effect for treatment location, as rural clinic treatment was responsible for a reduction of 1.27 points on distress scores ($b = -1.27, p = 0.042$), when controlling for all other predictors in the model. NON-PROFIT was not found to be a significant influence on distress ($b = 0.13, p = 0.822$). This model produced the lowest deviance and AICc values thus far (deviance = 5220.54, AICc = 5234.56). The hypothesized relationship between rural centers and distress was supported, but the for-profit effect was not. Figure 2.2 illustrates the RURAL main effect on DISTRESS, by AGE. Further investigation was undertaken to examine the potential cross-level interaction of the predictors on distress.

INSERT FIGURE 2.2 HERE

Random Intercept and Random Slopes Model, with Level 2 Cross-Level Interaction

The final model was used to examine the cross-level effects of level one factors AGE and GENDER on level two factors RURAL and NON-PROFIT. The deviance value for this model increased beyond the deviance from the previous two models, and the hypothesized relationships for this model were not supported. The level two interaction terms for RURAL x AGE ($t(14) = 0.58, p = 0.57$), NON-PROFIT x AGE ($t(14) = 0.66, p = 0.57$), RURAL x GENDER ($t(14) = 1.54, p = 0.145$), NON-PROFIT x GENDER ($t(14) = -1.49, p = 0.159$) were non-significant. The level two by gender interaction terms were approaching significance, though had we interpreted them, the hypothesized relationships would have been the opposite of what was predicted.

Model Selection

Values for the fixed and random parts of each model, as well as the model comparison statistics are listed in Table 2.2. Deviance values were used to indicate a rough approximation of model fit, but the second order version of Akaike's Information Criteria (AICc) was used for model selection purposes. This version corrects for model complexity by adjusting for the

number of parameters. Shown at the bottom of Table 2.2, the AICc values were derived from the following formula, where k equaled the number of parameters in a given model:

$$AICc = -2\text{LogLikelihood} + 2k + \frac{2k(k+1)}{(n-k-1)}$$

The optimal AICc value is the lowest given value, which was derived from Model 4, the level two main effects model (AICc = 5234.56). In addition, this model was compared to the unconditional model by subtracting the obtained deviance value in Model 4 from the deviance in Model 1. That value was then used to approximate a test of statistical significance, using a Chi Square test with degrees of freedom equal to the parameters in Model 4, minus the number of parameters in Model 1 ($LR\chi^2(5) = 18.19, p = .003$).

INSERT TABLE 2.2 HERE

Discussion

The data analyzed in this study are uniquely robust. Cancer studies are often biased entirely toward one gender or one type of cancer (Brocken et al., 2012). The data used in this paper are fairly heterogeneous, with more than 30 percent male patients, and patients ranging from 18 to 93 years of age. Although the variable was not used in these analyses, there were 11 types of cancer represented. Furthermore, these data were collected from 17 different cancer centers in nine U.S. states. Despite originating from many different cancer centers, all data were collected in the same way – through a standardized electronic screening tool – making comparisons more tenable.

This study presented several important findings. First, individual levels of psychological distress were found to be related to treatment setting. In fact, 15 percent of the variation in individual distress levels was a result of the effect of treatment center. This finding supports previous research that has indicated the importance of hospital or treatment center-level factors,

but extends this concept to psychological distress in cancer patients (Flocke, Strange, & Zyzanski, 1998). There was also a direct effect of age on distress, meaning that as age increased, distress levels decreased. This is consistent with much of the current literature (Schnoll & Harlow, 2001; van Scheppingen et al., 2011; Zabora, Brintzenhofeschoz, Curbow, Hooker, & Piantadosi, 2001). Additionally, there was significant variation in distress levels among mean age participants, when considering the between treatment center differences. In the optimal model, we found that, not only did older age reduce distress levels across clinics, but that patients treated in rural cancer clinics were more likely to experience decreasing levels of distress than their urban or suburban counterparts.

These findings support much of the previous behavioral research done with cancer patients, including support for a link between distress levels and patient age. The current study adds to the growing body of research in a way not previously found in the distress literature – by combining individual-level factors with clinic-specific characteristics. The emphasis on understanding and addressing distress and cancer patients has grown significantly over the past decade, and it is important that consideration be given to factors at every level.

Limitations

It should be noted that the majority of participants in this study reported a DT score above “4”, which is often used as the cut score, indicating clinical levels of distress. More than 75 % of those surveyed would have met this threshold. Though these findings are still in line with numbers reported by several researchers, including Graves et al. (2007), the percentage is higher than many of the previously stated prevalence rates, which have frequently ranged from 35 to 45% (Carlson et al., 2004; Carlson et al., 2003). The DT is often completed as a paper and pencil measure, and the patient may complete it in the presence of family members or treatment

center staff. It is possible that patients felt more comfortable to self-identify as experiencing significant distress when completing the electronic screening instrument by themselves. Moreover, while the DT is utilized as the primary indicator of psychological distress in this study, it was primarily developed as a screening tool. Some researchers have called into question the validity of diagnostic inferences made from the DT (Gessler et al., 2008; Mitchell, 2007).

Although the sample size in this study ($n = 1,112$) was sufficiently large for most statistical methods, it is often recommended that samples with 50 or more level two groups be used in HLM analyses, when possible (Hox, 2010). Although we utilized REML and effective sample size calculations to account for smaller level two groups, a larger level two sample would have likely produced more reliable estimates. Additionally, the level two sample was biased toward suburban, non-profit centers. Future studies should focus on rural, urban, and for-profit cancer centers.

The cross-sectional design of this study was a limitation, as was the secondary nature of the analyses. Although there were several types of cancers represented in the data, the amount of missing values prevented this variable from being used in the analyses. As cancer type has been previously linked to distress levels, adding it to the models would have been preferable (Brocken et al., 2015; Zabora et al., 2001). Although many demographic variables such as marital status, education, ethnicity, and income have not been consistently linked to distress levels, having additional information about the sample would have allowed for additional analyses (Andreu et al., 2012; Davis et al., 2011).

When considering the findings of this study, it should be noted the imposed restriction of range. This is a particular problem with scores from the DT. Possible scores on the DT are

limited to zero through ten and the majority of this sample reported scores that clustered on the upper half of the scale. This restriction could bias findings, including the attenuation of correlations.

Implications for Future Research

This study provided some potentially promising avenues for future research. Future studies are needed to help understand the effect of individual and clinic-level characteristics on psychological distress in cancer patient populations. Such studies should include samples with diverse individual characteristics that are being treated in both rural and non-rural clinics, as well as for-profit and non-profit organizations. This should include type and stage of cancer, as well as treatment center differences such as the number of behavioral health staff, and clinician characteristics and type of clinician conducting psychosocial assessments (e.g. oncology social worker, nurse, etc.). These studies should also take care to standardize assessments procedures in a way that allows for better comparison of results across centers. Though not significant in this study, there remains the possibility of cross-level interactions at the second-level of analysis, which if found, could contraindicate previously-held assumptions about risk and protective factors for psychological distress in oncology settings.

The multilevel methodology employed in this study may also be used to examine within and between-level factors in other areas germane to the mental health of cancer patients. Specifically, future studies should examine the effect of treatment setting on the presentation of traumatic stress, as well as depression, anxiety, and substance use disorders. These types of studies will help inform clinicians and improve strategies to better address behavioral concerns that result from cancer diagnosis and treatment.

More generally, additional large-scale distress studies are needed to better understand the factors involved in the presentation of severe psychological distress. The current literature on distress is largely comprised of homogeneous samples, and future research should utilize large-scale, diverse samples, when possible. Despite the limitations in number of clusters, the data in the current study presented an opportunity to examine a large, relatively heterogeneous sample of cancer patients. These type of data allow for wide-ranging implications of findings.

Implications for Practice

The stress of a cancer diagnosis and treatment is impactful and often results in the manifestation of behavioral health concerns – such as distress – which can directly impact the treatment process and greatly affect the patient’s quality of life. Oncology social workers and other clinicians have a responsibility to assess the degree to which a patient is experiencing psychological distress and, when elevated levels of distress are indicated, ensure that patients receive appropriate treatment. Ensuring effective management of concerns such as distress has been shown to improve fidelity to cancer treatments, meaning that behavioral health personnel can directly affect physical health outcomes in cancer patients (Gao, Bennett, Stark, Murray, & Higginson, 2010). This indicates that all cancer centers – if they have not already done so – should follow the American College of Surgeon’s Commission on Cancer mandate and integrate distress screening into routine cancer care.

While tools such as the Distress Thermometer are frequently used to detect symptoms of distress, clinicians should understand the characteristics which can predispose one to increased levels of distress and ensure that patients with those characteristics are monitored more closely. Tracking of at-risk patients can ensure that those affected are referred to services in a timelier

manner, and the timeliness of interventions has been directly related to more favorable behavioral health outcomes (Davis, 2004; Kazak et al., 2005).

This study specifically identified younger patients as being more likely to experience increased distress, with each year above the mean centered age accounting for an incremental decrease in distress. Clinicians should pay particular attention to symptoms of distress in younger patients. This may include the consideration of additional distress screening processes for younger patients. The problem checklist associated with the DT may provide some added utility for this group – meaning that problem areas identified by the checklist should receive immediate attention.

Furthermore, this study examined the role of treatment setting on distress symptom presentation. Results indicated that distress varied across cancer centers, meaning that clinicians should be aware of the clinic-level risk factors for distress and recognize that individual risk factors may vary, based upon those clinic-level characteristics. Specifically, patients were more likely to experience increased distress levels in suburban and urban clinics. Although not found in the current sample, some research has indicated that negative health outcomes may also be more likely in non-profit, than in for-profit centers (Flocke, et al, 1998).

Ultimately, cancer care is an interdisciplinary, collaborative process. Oncology social workers, psychologists, and other behavioral health personnel need to recognize the critical role that they play, not only in the mental wellbeing of cancer patients, but also in the long-term physical health of those patients. Proactively addressing psychological symptoms of distress can help improve treatment adherence and mitigate risks for serious physical health concerns.

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Appendix A: Tables and Figures

Table 2.1. *Sample Characteristics*

Level One Characteristics (n=1112)					
Distress ($M=5.06$, $SD=2.69$)	n	%	Age ($M=60.76$, $SD=12.94$)	n	%
0	106	9.5%	<40	56	5.0%
1	46	4.1%	40-49	135	12.1%
2	54	4.9%	50-59	315	28.3%
3	35	3.1%	60-69	339	30.5%
4	181	16.3%	70-79	181	16.3%
5	221	19.9%	80+	86	7.7%
6	128	11.5%			
7	110	9.9%			
8	120	10.8%	Gender	n	%
9	64	5.8%	Male	354	31.8%
10	47	4.2%	Female	758	68.2%
Level Two Characteristics (n=17)					
Community Type	n	%	n	%	
Non-Rural	663	59.6%	13	76.5%	
Rural	449	40.4%	4	23.5%	
Center Type	n	%	n	%	
For Profit	204	18.3%	6	35.3%	
Non Profit	908	81.7%	11	64.7%	

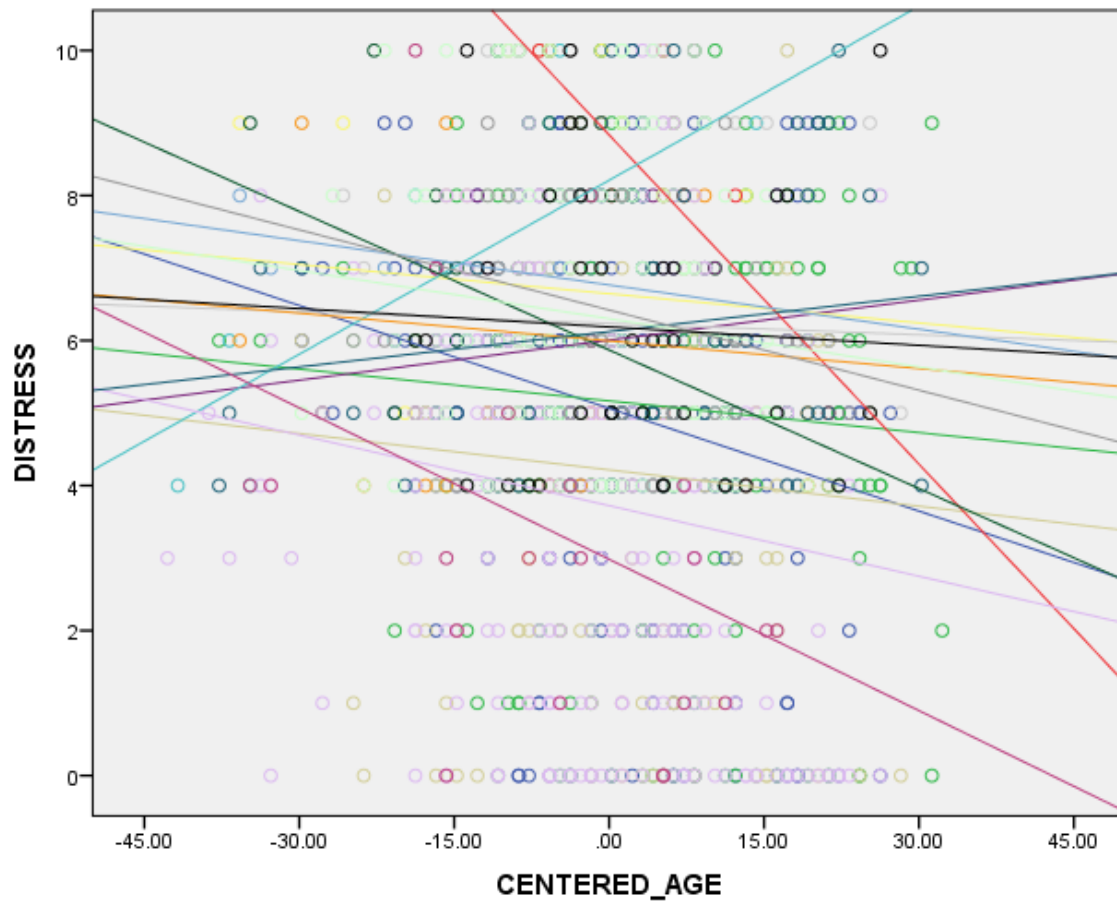


Figure 2.1. Slopes for Centered Age, Regressed on Distress Level
Note. Each line represents one cancer center

Table 2.2. Model Summary

	Model 1		Model 2		Model 3		Model 4		Model 5	
Fixed Effects	Coeff.	S.E.	Coeff.	S.E.	Coeff.	S.E.	Coeff.	S.E.	Coeff.	S.E.
Intercept (γ_{00})	5.72***	0.29	5.58***	0.31	5.71***	0.37	5.93***	0.48	5.41***	0.69
AGE (γ_{10})	--	--	-0.02***	0.01	-0.02*	0.01	-0.01*	0.01	-0.03	0.02
GENDER (γ_{20})	--	--	0.14	0.17	-0.02	0.23	0.04	0.23	-0.40	0.48
RURAL (γ_{01})	--	--	--	--	--	--	-1.27**	0.57	-1.62	0.95
NON-PROFIT (γ_{02})	--	--	--	--	--	--	0.13	0.58	1.03	0.93
RURAL(x)AGE (γ_{11})	--	--	--	--	--	--	--	--	0.01	0.02
NON-PROFIT(x)AGE (γ_{12})	--	--	--	--	--	--	--	--	0.01	0.02
RURAL(x)GENDER (γ_{21})	--	--	--	--	--	--	--	--	0.75	0.49
NON-PROFIT(x)GENDER (γ_{22})	--	--	--	--	--	--	--	--	-0.87	0.58
Random Effects										
Level 1										
Residual (σ^2)	6.32	--	6.25	--	6.18	--	6.16	--	6.17	--
Level 2										
Intercept (τ_{00})	1.19	--	1.10	--	1.59	--	1.43	--	1.78	--
Intercept/AGE (τ_{01})	--	--	--	--	0.00	--	0.00	--	0.00	--
Intercept/GENDER (τ_{02})	--	--	--	--	0.22	--	0.23	--	0.18	--
AGE (τ_{11})	--	--	--	--	0.01	--	0.02	--	0.03	--
GENDER (τ_{12})	--	--	--	--	-0.37	--	-0.25	--	-0.42	--
Model Fit										
Deviance	5238.73		5234.15		5226.22		5220.54		5228.014	
Parameter	2		2		7		7		7	
AICc	5242.74		5238.16		5240.23		5234.56		5242.03	

Note. *** $p < .001$, ** $p < .05$, * $p < .01$

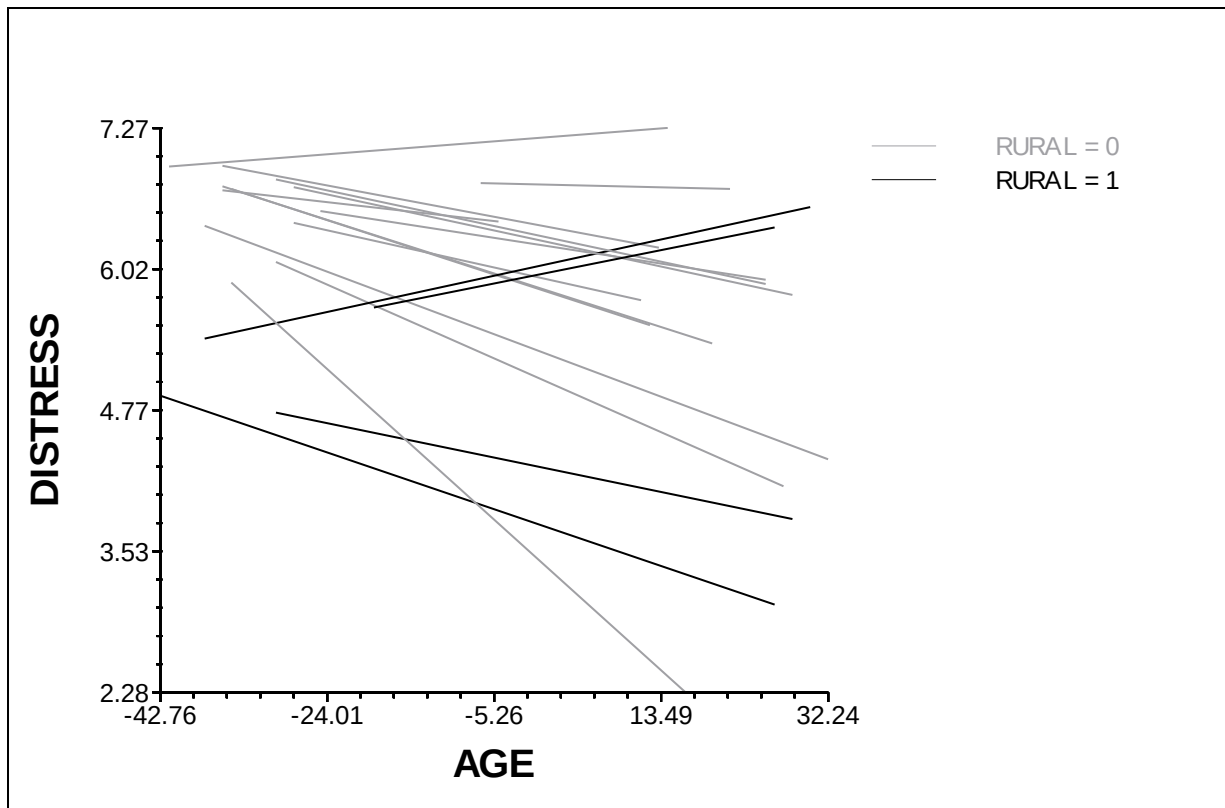


Figure 2.2. *Model 4 - Main Effect of Rural Clinics*

Appendix B: Mixed Models

Mixed Model 1

$$DISTRESS_{ij} = \gamma_{00} + u_{0j} + r_{ij}$$

Mixed Model 2

$$DISTRESS_{ij} = \gamma_{00} + \gamma_{10} * AGE_{ij} + \gamma_{20} * GENDER_{ij} + u_{0j} + r_{ij}$$

Mixed Model 3

$$DISTRESS_{ij} = \gamma_{00} + \gamma_{10} * AGE_{ij} + \gamma_{20} * GENDER_{ij} + u_{0j} + u_{1j} * AGE_{ij} + u_{2j} * GENDER_{ij} + r_{ij}$$

Mixed Model 4

$$DISTRESS_{ij} = \gamma_{00} + \gamma_{01} * RURAL_j + \gamma_{02} * NON_PROFIT_j + \gamma_{10} * AGE_{ij} + \gamma_{20} * GENDER_{ij} + u_{0j} + u_{1j} * AGE_{ij} + u_{2j} * GENDER_{ij} + r_{ij}$$

Mixed Model 5

$$DISTRESS_{ij} = \gamma_{00} + \gamma_{01} * RURAL_j + \gamma_{02} * NON_PROFIT_j + \gamma_{10} * AGE_{ij} + \gamma_{11} * RURAL_j * AGE_{ij} + \gamma_{12} * NON_PROFIT_j * AGE_{ij} + \gamma_{20} * GENDER_{ij} + \gamma_{21} * RURAL_j * GENDER_{ij} + \gamma_{22} * NON_PROFIT_j * GENDER_{ij} + u_{0j} + u_{1j} * AGE_{ij} + u_{2j} * GENDER_{ij} + r_{ij}$$

CHAPTER III

SELF-REPORTED DISTRESS AND POSTTRAUMATIC STRESS

This manuscript (Chapter 3) has not been submitted for publication and will not be published prior to submission of the final version. Reviews and subsequent revisions were conducted in consultation with my dissertation committee. Reviewers included my dissertation committee: Drs. Matthew T. Theriot (Chair), Cindy Davis, William Nugent, Mary Held, and Russell Zaretzki. I was the sole-author on this original manuscript. My current plan is to submit this manuscript for publication in *Psycho-Oncology*, once approved by the aforementioned committee.

Abstract

Introduction: Research is beginning to show a link between distress and increased levels of posttraumatic stress symptoms (PTSS). Sustained distress and PTSS have been shown to result in numerous negative outcomes in both mental and physical health. Though cancer centers across the United States have begun routine assessment of psychological distress, assessment of PTSS is less routine. Understanding the mechanisms by which distress results in, or influences, PTSS will aid clinicians in developing protocols to more effectively identify PTSS in cancer patients.

Methods: Survey data were collected during intake at nineteen cancer centers across the continental United States. Patients reported distress ratings on the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT), responded to questions related to PTSS, and provided information about current symptoms and social support systems. Hypotheses were tested using a conditional process model in the PROCESS macro for SPSS. Paths were provided for direct and indirect effects, including moderation and mediated moderation.

Results: Findings indicated that, while distress scores were influential in the total model, the direct effect of distress on PTSS was negated by the model's indirect effects. Furthermore, the effects of social support and age were independent protective factors, there was a moderation effect that varied across groups. Lastly, the addition of a mediator variable representing physical cancer symptoms helped explain the relationship between distress and PTSS.

Discussion: This paper presents an important step in better understanding the relationship between distress and PTSS. The findings support previous research, which have suggested that distress levels and PTSS are related, as well as the proposed moderating effects of age and social support. It adds to the growing knowledge base by providing evidence for a potential

mechanism by which distress relates to PTSS. Furthermore, it suggests that age and social support may be protective factors for certain groups and risk factors for others. Finally, this study provides suggestions for potential next steps that could lead to improvements in day-to-day psychosocial screenings in cancer treatment settings.

Introduction

Cancer diagnosis and treatment is a stressful process, with effects that have been compared to those seen in individuals who have experienced active combat exposure (Davis et al., 2011; Smith et al., 1999). In response to these stressors, cancer patients and their families frequently contend with severe distress, as well as acute or posttraumatic stress disorder (PTSD), or partial posttraumatic stress symptoms (PTSS) (Varela et al., 2013). There are projected to be 1,688,780 new cancer cases in 2017, therefore, concerns such as distress and posttraumatic stress should be urgently addressed within the psychosocial oncology literature (American Cancer Society, 2017; Siegel et al., 2016).

Distress has been recognized as the “sixth vital sign”, and as such, is a primary psychological concern in cancer care (Bultz et al., 2011; Holland et al., 2007).

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.

Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (Holland et al., 2013, p. 192)

Severe distress is often found in cancer patient populations. In response to a common concern, the American College of Surgeons’ Commission on Cancer (CoC) required that all accredited cancer centers implement the monitoring of distress in routine patient care by 2015. As a result, treatment centers have begun using tools such as the National Comprehensive

Cancer Network (NCCN) Distress Thermometer (DT) in daily practice. The DT is frequently used due to its utility, ease of use, and brevity (Jacobsen, 2007).

Not surprisingly – like distress – cancer patients have been found to experience symptoms of posttraumatic stress at rates significantly higher than those found within the general public (Pujol et al., 2013; Vin-Raviv et al., 2013). More common than full PTSD, prevalence rates of PTSS in cancer patient populations have been reported up to 23% (Vin-Raviv et al., 2013). Unlike distress, although effective methods for identifying traumatic stress exist, the associated costs and patient participation often make additional or intensive assessment unrealistic (Fielding & Lamb, 2013; Jacobsen, et al, 2005). As such, understanding the relationship between PTSS and a commonly-assessed domain such as distress could help improve future detection of PTSS in cancer patients.

Furthermore, cancer-related distress and PTSS may not abate without appropriate psychological treatment (Carlson et al., 2010). Untreated chronic distress and PTSS have been linked to increased risk for other mental health problems, the onset of health concerns such as cardiovascular disease, and premature death (Boscarino, 2004). Research has documented efficacious interventions for cancer patients experiencing severe distress or traumatic stress, as well as the importance of beginning these treatments as early as possible (Bryant, 2003; Chan et al., 2011; Faller et al., 2013; Holland et al., 2010; Jacobsen et al., 2007; Luckett et al., 2011; Speca et al., 2000). Thus, understanding the role of distress and PTSS, along with their relationship to the stress resulting from cancer is critical to improving patient care and outcomes (Cordova et al., 2001; Kwekkeboom et al., 2002). This also means that the identification of symptoms both distress and PTSS should be considered an essential piece of routine cancer care.

Though the literature in this area is somewhat limited, a few studies have identified a relationship between high levels of distress and PTSS (Balder et al., 1997; Pujol et al., 2013). High levels of distress have been associated with posttraumatic stress symptoms, and the posttraumatic stress symptoms most commonly-linked to cancer patients are those of intrusive re-experiencing (Kangas et al., 2002; Pujol et al., 2013; Varela et al., 2013). Physical cancer symptoms such as gastrointestinal problems have been linked to distress and long-term anxiety, which suggests a possible relationship between physical symptoms, distress, and anxiety-related concerns such as PTSS (Carlson et al., 2013).

Age has been found to moderate the relationship between cancer-related distress and posttraumatic stress symptoms (Rourke et al., 2007). Social support has been frequently identified as a potential protective factor for significant distress which is, in turn, related to traumatic stress (Andreu et al., 2012; Carlson et al., 2013; Singer et al., 2012). Although social support has been linked to both distress and PTSS, some researchers have indicated that social support may not be a direct predictor of PTSS (Swartzman, Sani, & Munro, 2016).

The purpose of this study was to examine a hypothesized path model (see Figure 3.1) that suggests a relationship between distress and PTSS, by way of physical cancer symptoms. As social support and age are the most frequently-cited moderators of distress and PTSS, they were also included in the model. The following hypotheses were to be evaluated:

H₁: Increased levels of psychological distress are associated with higher levels of PTSS.

H_{2a}: Older age will reduce the effect of distress on PTSS.

H_{2b}: Higher levels of social support will reduce the effect of distress on PTSS.

H₃: The relationship between distress and PTSS will be mediated by physical symptoms.

H_{4a}: The effect of distress on physical symptoms will be moderated by age.

H_{4b}: The effect of distress on physical symptoms will be moderated by social support.

H_{5a}: The mediation effect will be moderated by age.

H_{5b}: The mediation effect will be moderated by social support.

INSERT FIGURE 3.1 HERE

Methodology

Data and Sample

Data were collected as part of routine intake procedures at nineteen cancer centers, located in nine states across the continental US. This sample included patients from geographically diverse areas and included clinics located in rural, suburban, and urban areas. During intake, patients were asked to complete an electronic psychosocial assessment and data were collected by the health informatics company. This assessment included questions regarding current cancer symptoms, available social support, as well as mental health indicators such as levels of psychological distress and PTSS. The assessment was completed on a tablet device, and questions were available in both English and Spanish. De-identified data were provided to the investigators and IRB approval was obtained.

Measures

Distress Thermometer (DT). The DT was utilized in gathering self-report information about each patient's level of psychological distress. Participants were asked to rate their level of distress in the past week, from 0 to 10, with 10 indicating severe distress. This variable was identified as the primary predictor for statistical modeling purposes. Akizuki et al. (2005) reported sensitivity and specificity values for the DT at .84 and .64, respectively. Similar values have been found in other studies as well (Vodermaier, 2009).

Posttraumatic Stress Symptoms (PTSS). Three questions were asked to identify potential PTSS. These questions were: “In the past two weeks, how often have you felt like you are reliving your diagnosis of cancer?”, “In the past two weeks, how often have you had "nightmares" or "disturbing dreams" about your cancer?”, and “In the past two weeks, how often have you been bothered by intrusive thoughts or images about your cancer?”. The items were scored on a Likert-type scale, from “never or rarely” to “all or most of the time”. Responses were totaled to create a sum of PTSS symptoms with scores ranging from zero to twelve, which was used as the primary outcome variable in this study.

Physical Symptoms. Cancer-related physical symptoms were also included in the assessment. Patients were asked to give a series of binary (yes/no) responses to indicate if they had experienced problems with pain, tiredness or fatigue, nausea or vomiting, sexual dysfunction or lack of interest in sex, somatic disturbances, or bowel difficulties. These responses were combined into a cancer symptom score, where lower values indicated more severe symptomology and higher values were representative of less symptoms.

Social Support. Social support levels were assessed with ordinaly-scaled items, with possible responses ranging from “strongly disagree” to “strongly agree”, with five total response categories. Respondents were asked if they had friends or family to: help with life responsibilities, help with transportation to treatment, help with financial concerns, to ask for advice, to provide emotional support, to provide comfort and understanding, or to help with the overall difficulty of cancer treatment. Item responses were summed to create a total score representing social support, with higher values indicating higher levels of positive social support.

Data Analysis

Data were analyzed using IBM Statistical Package for the Social Sciences (SPSS), version 24.0. Univariate descriptive statistics and bivariate correlations were assessed prior to model construction, as were the regression model assumptions. A power analysis was conducted using G*Power 3.1 and the results indicated that there was a sufficient sample size to detect a small effect, given a power of .80 an alpha value of .05. Upon completion of data screening, a conditional process analysis was conducted using Hayes' Model 76 in the PROCESS SPSS macro to test the study hypotheses (Hayes, 2013).

Scores from all multi-item scales were assessed to determine if there was sufficient internal consistency using Cronbach's Alpha. Reliability analyses were conducted and there were no problematic items identified. Coefficient estimates indicated sufficient reliability for the PTSS, symptoms, and social support scales, with Cronbach's Alpha values of .70, .89, and .69, respectively.

Results

Responses for more than 1,140 patients were recorded. Participants with missing values on any of the predictor or outcome variables were removed listwise, as a function of the conditional process analysis. The deleted cases included any participant with a missing value in any of the study variables. These cases were analyzed to determine if there were any important differences between their responses on other study variables and the remaining sample. No differences were identified and the omission of these cases proved inconsequential to the attainment of the desired statistical power, so imputation was not used. This left a total 1,119 cases in the final sample. In order to better describe the analyzed data, descriptive statistics were analyzed using the reduced sample. Demographic information captured in this study was limited

to age and gender. Age was measured in years and gender was measured dichotomously – male and female. The sample consisted of 31.8% male and 68.2% female patients. Participants ranged in age from 18 to 93 ($M=60.58$, $SD=12.84$). More than twelve types of cancer were represented in these data, with the largest groups being breast cancer (33.2%) and lung cancer (11.3%). This variable was excluded from analysis, however, as 35% of participants did not specify a cancer type.

Seventy-eight percent of participants responded with a “4” or higher on the DT, indicating significant distress ($M=5.07$, $SD=2.70$). Though the majority of patients met this clinical cut-off, DT scores have been found to vary greatly, with rates regularly reported from 30 to 70 percent (Bultz et al., 2005; Graves et al., 2007; Hegel et al., 2006; Henselmans et al., 2010; Hollingworth et al., 2013). The percentage of participants indicating some degree of PTSS was within the ranges found in other studies, at 18.2% (Vin-Raviv et al., 2013).

Bivariate correlations indicated a moderate correlation between distress scores and PTSS ($r = .377$, $p < .001$). There was also a significant negative correlation between distress scores and the physical cancer symptoms scores ($r = -.669$, $p < .001$), as well as distress and social support ($r = -.350$, $p < .001$). A small, but significant correlation was found between distress and age ($r = -.091$, $p = .002$). PTSS was also correlated negatively with symptom scores ($r = -.523$, $p < .001$), social support ($r = -.077$, $p < .001$), and age ($r = -.125$, $p < .001$). Gender was not significantly correlated with any of the study variables, except age ($r = -.195$, $p < .001$). Correlations and mean values for all study variables are shown in Table 3.1.

INSERT TABLE 3.1 HERE

In Step 1 of the conditional process model, distress was regressed on the proposed mediator, cancer symptoms. Social support and age were added as moderators. In order to

control for the effect of gender, it was added to the model as a covariate. This intermediate model explained nearly 50% of the variance in symptom scores ($R^2 = .491$, $F(6,1112) = 179.07$, $p < .001$). Distress was directly related to symptom scores ($t(6,1112) = -3.48$, $p < .001$), as were social support ($t(6,1112) = 8.40$, $p < .001$), and the interaction effect between distress and social support ($t(6,1112) = -7.73$, $p < .001$).

In Step 2, the model accounted for the direct effect of distress on PTSS, as well as the mediation, moderation, and mediated moderation effects. The final model accounted for 31% of the total variation in PTSS ($R^2 = .310$, $F(9,1109) = 55.42$, $p < .001$). Cancer symptom scores predicted PTSS ($t(9,1109) = -8.48$, $p < .001$), as did the interaction between symptoms and social support ($t(9,1109) = 4.07$, $p < .001$) and age ($t(9,1109) = 4.25$, $p < .001$). Similarly, social support alone ($t(9,1109) = -3.09$, $p = .002$), age alone ($t(9,1109) = -4.12$, $p < .001$), and the distress/age interaction ($t(9,1109) = 2.13$, $p = .034$) were statistically significant predictors of PTSS. Specifically, increases in age or social support were related to decreased levels of PTSS. Mediation was observed, as distress did not have a direct effect on PTSS ($t(9,1109) = -1.51$, $p = .131$) when controlling for the other variables. As was the case with the direct effect of distress on PTSS, the distress and social support interaction did not have a significant effect on PTSS ($t(9,1109) = .722$, $p = .470$). Figure 3.2 represents all paths in the conditional process model, with coefficient values listed for each relationship.

INSERT FIGURE 3.2 HERE

Significant moderation was demonstrated in the conditional direct effects of distress on PTSS. Specifically, this relationship was moderated for patients one standard deviation above the mean age, at all levels of social support. The strongest effects were shown in patients at one standard deviation above the mean age, at both mean ($p < .001$, 95% CI [.056, .171]) and one

standard deviation above mean levels of social support ($p < .001$, 95% CI [.061, .192]).

Moderation also occurred at one standard deviation below mean social support levels and one standard deviation above the mean age ($p = .012$, 95% CI [.022, .173]), and in those at mean age with mean levels ($p = .001$, 95% CI [.028, .112]) and above mean levels of social support ($p = .003$, 95% CI [.029, .143]). Examination of this direct effect moderation indicates that increased levels of social support and at-or-above mean age are related to an increase in the positive relationship between distress levels and PTSS. This means that, although older age and increased social support were associated with decreased levels of PTSS, the buffering effect of social support may not apply to older adults.

Moderated mediation occurred at all levels of the moderating variables, as shown in Table 2. Effects were evaluated by bootstrap estimation, with confidence intervals generated based upon 5,000 samples. Statistically significant relationships were indicated by confidence intervals not containing zero. Results indicate that as levels of social support rise, the difference between age groups increases. The largest effects occurred when social support levels were one standard deviation below mean age and at ($b = .228$, $SE = .024$, 95% CI [.181, .276]), or one standard deviation above ($b = .235$, $SE = .035$, 95% CI [.166, .305]) mean levels of social support. Unlike the results seen in the direct effect moderation, this moderated mediation indicates that – when considering the physical symptoms associated with cancer – the reduced protective factor of social support most negatively impacts younger cancer patients.

INSERT TABLE 3.2 HERE

Discussion

Of the eight hypothesized relationships, the results supported seven. Findings from the conditional process model indicated that increased levels of distress are predictive of PTSS, but

that this relationship may be a function of physical symptoms. Both older age and increased levels of social support were shown to decrease PTSS. Nonetheless, the combined moderation effect of these variables on the relationship between distress and PTSS affected an increase in PTSS for older adults with higher levels of social support. Social support also functioned as a moderating influence on the distress to symptom score path, but the hypothesized moderation of age was not supported. Additionally, the observed mediating effect of physical symptoms was conditional upon levels of age and social support. This moderation was reflective of higher PTSS in younger patients with moderate to high levels of social support, when considering the physical symptom mediation.

Interestingly, physical symptoms not only mediated the relationship between distress and PTSS, but the direct relationship between distress and PTSS was significant as well. Specifically, increased distress was related to more physical symptoms. This was consistent with previous studies, which have reported similar findings (Clark et al., 2011; Grassi et al., 2013; Graves et al., 2007).

This study provides important evidence for the potential relationship between distress and PTSS, as well as a better understanding of how age and social support may help insulate certain groups from the deleterious effects of high levels of psychological distress, and the way in which the physical effects of cancer can alter this relationship. In addition, much of the literature on distress and PTSS in cancer patients is limited to homogenous groups. Often, studies are conducted with samples limited to one type of cancer or gender, which limits generalizability. This study is derived from a sample of patients with numerous types of cancer, and although not evenly split by gender, is more than 30% male.

Limitations

This study was cross-sectional and utilized a secondary data source of self-reported data. As such, there were several variables which were not available for analysis. In particular, this study was limited in its ability to assess some key demographic variables. The analyses conducted were not able to account for potential differences due to ethnicity, education, or socioeconomic status. As income has been previously reported as a significant predictor of distress, its omission from the data must be considered a limitation (Carlson et al., 2004). Additionally, though these data represent a variety of cancer diagnoses, the large amount of missing data in the cancer type variable limited its utility in this study.

It has been suggested that specificity in identifying the type of social support is important when determining its relationship with mental health outcomes in healthcare settings. The data in this study were limited to positive social support, however, studies have shown that negative social support may also be significantly related to depression and distress (Ahn, Kim, & Zhang, 2016; Cox, Buhr, Owen, & Davidson, 2015). Moreover, social support may need to be more clearly defined when establishing a link to PTSS or distress (Swartzman et al., 2016).

Additionally, the DT was used as an indicator of distress in this study. Although the DT has been praised for its value within clinical settings, it was developed as a screening tool. Its use as a diagnostic instrument may be suspect and should be considered when evaluating the findings of the current study (Gessler et al., 2008; Mitchell, 2007).

Restriction of range must also be considered with these data. Indicators of physical symptoms, posttraumatic stress, and social support are measured ordinally. In addition, DT scores are recorded as zero to ten responses, and the mean was nearly six. Restriction of range may result in weakened correlations and biased findings.

Implications for Research

Future studies should further examine the relationship between distress and PTSS. This could include examining the utility of specific measures – such as the DT – in identifying PTSD or PTSS. While this study was limited to three indicators of PTSS, and although a link between DT scores and PTSS was identified, additional items of measures of PTSS would allow for more in-depth investigation in the future. This could also include standardized PTSD measures, though as mentioned earlier in this paper, partial PTSS are more commonly reported than clinical PTSD. In addition, researchers should examine the effect of social support on the relationship between distress and PTSS, with added specificity in the various domains of social support.

The mean distress rating given in this sample was above that traditionally considered as the cut score for clinically-significant distress. While the body of research generally supports the use of the DT as a screening instrument, the elevated distress levels reported in this sample indicate the potential need for additional research to examine the cut score which would provide optimal sensitivity and specificity. Additionally, if the DT is to be used as a potential screening instrument for other mental health concerns such as PTSS, a cut score should be established to represent those domains.

Perhaps most importantly, this study presents the possibility that, though distress and PTSS appear to be linearly related, their relationship may be a function of another variable. Specifically, this study found that, when considering physical cancer symptoms, there was no direct relationship between distress and PTSS. Future research should examine this link to determine to what extent distress and PTSS are related, independent of other factors.

Implications for Practice

Research indicates that the most effective way to identify traumatic stress in cancer patients is to conduct multidimensional assessments at different times and in different ways (Poder et al., 2008; Smith et al., 1999). Unfortunately, conducting assessments in that way can be very costly and time consuming, and simply not practical in many clinics. Not surprisingly, the clinics that are unable to outlay the resources needed are often those that treat the underserved. In light of this reality, it is important to identify those most at risk and to improve screening procedures so that they are more efficient and maximize available resources. This includes utilizing current measurement instruments in new and innovative ways. The DT has been shown in previous research to be an effective tool for not only identifying clinical distress, but also the symptoms of other depressive and anxiety-related disorders (Akizuki et al., 2005; Hegel et al., 2008). Given the findings of the current study, as well as the fact that PTSD is an anxiety disorder and its symptoms have been previously connected to distress levels, it stands to reason that there could be some potential overlap in the screening utility of this instrument. Clinicians should bear in mind that elevated scores on the DT may indicate greater possibility for PTSS, so patients reporting extreme distress scores should be assessed for PTSS. This would provide an indicator for clinicians in centers without the resources to screen every patient for PTSS.

Additionally, clinicians should consider the screening utility of tools such as the DT. While the DT may provide adequate sensitivity, the specificity may be less desirable. A large portion of the patients surveyed in this study reported increased levels of distress. Improperly attributing clinical distress to patients may result in the misallocation of resources and unneeded treatment for the patient.

Clinicians should also understand that, although older patients may be less likely to experience distress or PTSS separately, the mechanism by which one transitions from distress to PTSS may be altered by age. Similarly, social support may provide a buffer for the stress of cancer, and it may complicate the experience for certain groups. If this is the case, then clinicians should consider that programs designed to enhance social support networks may be helpful for some patients and potentially harmful for others.

Similarly, younger patients largely experienced increased levels of distress. Clinicians should consider expanding assessment protocols for at-risk groups, such as younger cancer patients. This could include ensuring that these patients complete the DT's 39-item problem checklist and quickly identifying any reported problem areas.

These findings also provide an important opportunity to improve cooperation among multidisciplinary cancer teams. Studies have consistently shown that prolonged, untreated distress and PTSS can contribute to stress-related negative health outcomes (Boscarino, 2004). Moreover, untreated distress and PTSS can worsen treatment outcomes by altering patient health behaviors such as treatment adherence (Andersen et al., 2007; Graves et al., 2007; Hurria et al., 2009; Rohan, 2012; Wade et al., 2005; Zabora et al., 2001). Social workers and Psychologists can inform physicians and nurses of mental health concerns, and nurses and physicians can communicate health-related factors that may make patients more likely to experience distress or PTSS.

These findings also indicate that cancer patients should be made aware of the potential link between distress and PTSS. If untreated distress does make the presentation of PTSS more likely, patients should indicate symptoms to their providers as early as possible. Although treatments can be effective for psychological concerns such as distress, early treatment is

important (Brocken et al., 2015). If cancer patients are educated on the long-term consequences of chronic distress and the increased odds of developing PTSS, then they may be more likely to avail themselves of needed services.

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Appendix: Table and Figures

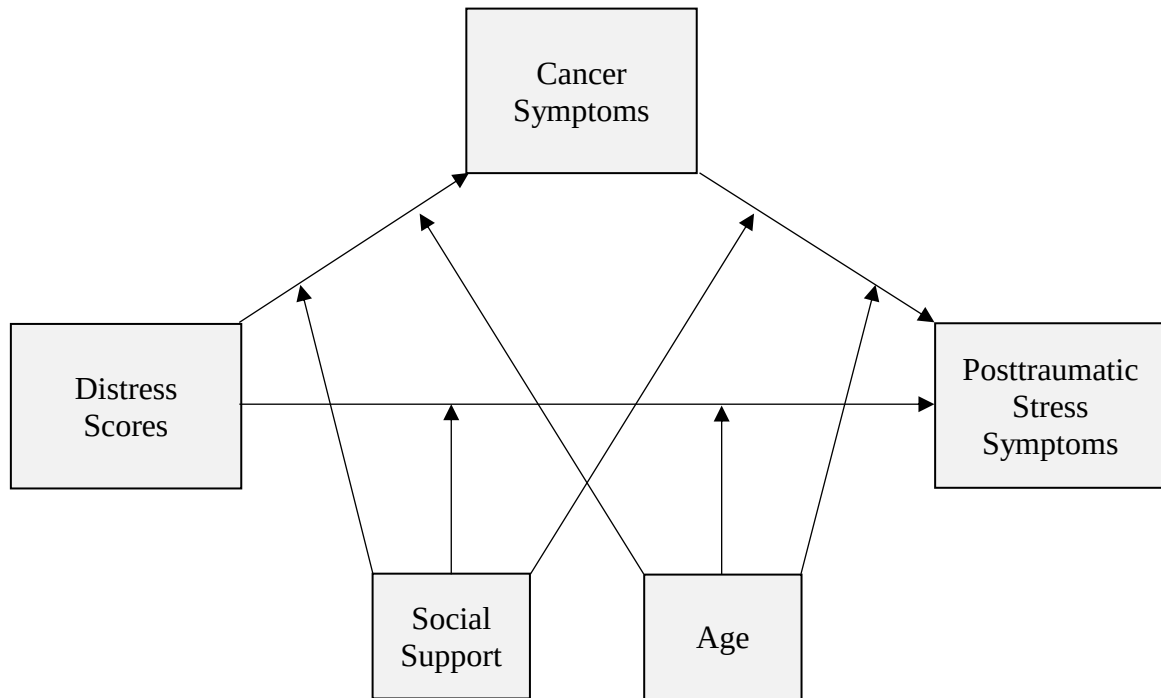


Figure 3.1. *Conceptual diagram of conditional process model*

Table 3.1. *Descriptive Results*

Bivariate Correlations and Descriptive Statistics (N=1,119)								
	1	2	3	4	5	6	M	SD
1. Distress	-						5.07	2.70
2. PTSS	.377***	-					4.32	1.63
3. Symptoms	-.669***	-.523***	-				3.71	0.70
4. Social Support	-.350***	-.077**	.299***	-			17.54	13.39
5. Age	-.091**	-.125***	.153**	.017	-		60.58	12.84
6. Gender	.036	.008	.006	.006	-.195***	-		

Note: *p<.05 **p<.01 ***p<.001

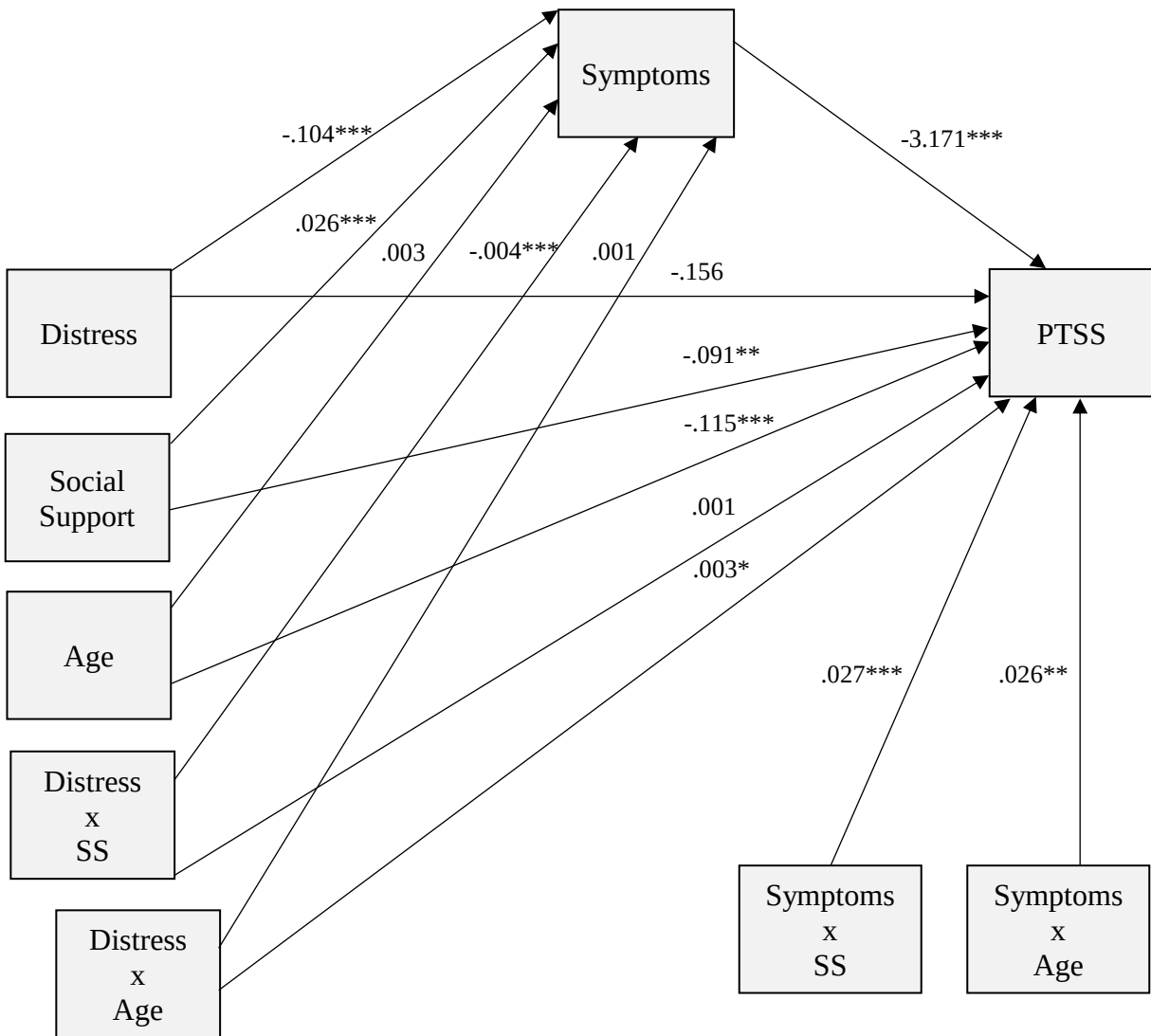


Figure 3.2. Path diagram and coefficient values for conditional process model

Note. $*p < .05$ $**p < .01$ $***p < .001$

Table 3.2. *Bootstrap Estimates for Moderated Mediation Effects*

Conditional Indirect Effects of Distress on PTSS at values of the moderators (Mediated by Symptom Score)					
Social Support	Age	Effect	Boot <i>SE</i>	95% Boot CI	
				LL	UL
4.1451	47.7334	0.1820	0.0317	0.1246	0.0855
4.1451	60.5773	0.1411	0.0261	0.0955	0.1178
4.1451	73.4212	0.1041	0.0273	0.0588	0.1690
17.5398	47.7334	0.2278	0.0243	0.1812	0.2757
17.5398	60.5773	0.1718	0.0187	0.1357	0.2102
17.5398	73.4212	0.1197	0.0258	0.0723	0.1748
30.9344	47.7334	0.2354	0.0352	0.1664	0.3053
30.9344	60.5773	0.1643	0.0286	0.1100	0.2197
30.9344	73.4212	0.0972	0.0355	0.0326	0.1702

Note: Relationships are statistically significant when the confidence interval does not contain zero.

CONCLUSION

This dissertation addressed the relationship between contextual factors (e.g. age, gender, treatment setting, etc.) and distress, as well as the relationship between distress and posttraumatic stress symptoms (PTSS). A literature review was conducted to better understand the state of the current research on distress and PTSS in cancer patient populations. The aims of this paper were to: define distress and PTSS, to provide a better understanding of risk and protective factors, and to examine the relationship between the two conditions.

The term distress was coined as a method to better encapsulate the feelings of depression, anxiety, and fear that often occur during cancer treatment, and to do so in a less stigmatizing manner (Holland et al., 2010). Distress is commonly seen in cancer patients and has become a focus of those within the cancer community, so much so that distress screening has now become a standard procedure for many cancer centers (Jacobsen, 2007). Tools such as the National Comprehensive Cancer Care Network (NCCN) Distress Thermometer (DT) have allowed for the assessment of distress in an efficient and inexpensive manner, making screening processes more easily adoptable (Carlson et al., 2010).

PTSS is term used to describe symptoms of Posttraumatic Stress Disorder (PTSD) that are observed, but do not rise to the level of full clinical diagnostic standards (Varela et al., 2013). PTSD is often seen in combat veterans and, although PTSD prevalence rates are often observed to be lower in cancer patients than combat veterans, cancer patients do experience PTSD at higher rates than in the general population. Furthermore, rates of cancer-related PTSS have been found to be 20 percent or higher (Vin-Raviv et al., 2013). Unlike distress, symptoms of posttraumatic stress are often not regularly monitored in cancer settings, with costs and time reported to be the primary obstacles (Fielding & Lam, 2013; Jacobsen et al., 2005).

Understanding the factors that relate to the presentation of distress and PTSS in cancer patients is an important next step in the evolution of psychosocial cancer care. While age and physical health symptoms have often been related to both, many of the individual characteristics commonly associated with other mental health conditions have not been found to be consistently related to distress or PTSS in cancer patient samples (Andreu et al., 2012; Clark et al., 2011; Grassi et al., 2013; Graves et al., 2007). Disagreement and inconsistent findings in the literature may be a result of samples that are often biased toward one group (Brocken et al., 2015). Although there are few studies that have examined the intersection of distress and PTSS, those that have indicated that higher levels of distress are correlated with higher rates of PTSS (Pujol et al., 2013).

Throughout the review of the literature, it became clear that a third construct was closely interrelated with both distress and PTSS – posttraumatic growth (PTG). PTG was not represented within the data used for this dissertation, but it clearly falls on the same continuum of responses to cancer-related stress and remains an important area for future research. Factors that predispose or insulate one to distress or PTSS, such as age, social support, and gender, are often also related to the promotion of PTG, meaning that they may share similar presentation pathways (Cordova et al., 2007). Furthermore, although PTG has been found to be positively correlated with increased distress, it may also serve as a long-term protective factor (Silva et al., 2012; Thornton et al., 2006). There remains a need for research examining the direct relationship between distress, PTSS, and PTG. This should also include potential interventions to promote PTG, as initial research suggests it as a path toward improving outcomes post-cancer-treatment (Silva et al., 2012).

The literature review provided a framework for the conceptualization of papers 2 and 3. In paper 2, electronic intake data from 17 cancer treatment centers were used in hierarchical linear analyses to examine differences in reported distress levels within and between cancer centers. Individual characteristics such as gender and age were included, as were clinic characteristics, such as whether the clinic was located in a rural or suburban area and whether the center was a for-profit or non-profit organization. Findings reinforced prior work that indicated a negatively-correlated relationship between age and distress, but this relationship was found to vary among treatment centers. Additionally, patients treated in rural clinics were less likely to experience higher levels of distress than patients treated in their suburban counterparts. This provides important context for the presentation of distress and indicates an important area of need for future research.

The final paper – paper 3 – integrated PTSS in order to examine the possible link with distress. As previously stated, earlier research has indicated a relationship between increased distress and PTSS, but that literature is limited and this is a new area. A conditional process model was constructed to evaluate hypothesized moderating relationships of age and social support on the path between distress and PTSS, as well as a potential mediating relationship with distress influencing PTSS by way of physical symptoms. Additionally, the age and social support moderators were modeled on the mediation path to check for moderated mediation. Results of the study indicated that, not only were higher levels of distress related to increased PTSS, but that the relationship was moderated by patient age. Interestingly, higher distress levels were also related to greater symptom presentation, and physical symptoms were related to increased levels of PTSS. The relationship between distress and PTSS was completely mediated

by physical symptoms, and the distress to PTSS path was not significant once the mediation path was added.

Recommendations for Future Research

This dissertation indicates the need for several important areas of future research. First, as indicated in the review of available literature, there is a need for studies to improve our understanding of risk and protective factors. A primary issue identified in this area is the limitations imposed by cancer research that is frequently done with small samples, or with samples composed entirely of one gender or type of cancer (Brocken, Prins, Dekhuijzen, & van der Heijden, 2012). There also appear to be important differences in the way that certain cancers effect the presentation of distress and PTSS (Pujol et al., 2013). In the future, researchers should take extra steps to ensure that heterogeneous samples are used in distress and PTSS research.

Another important finding from this dissertation was the relationship between distress and PTSS and how that relationship may be altered by factors such as age, social support, and physical symptoms. Additional characteristics should be examined and replication should occur. Future studies are needed to expand this new body of research and to examine the ways that this knowledge can translate to practice.

Additionally, if distress is related to PTSS and PTSS is not regularly assessed during cancer treatment, then the utility of current distress measures should be examined to determine if they can provide early detection of PTSS. Previous studies have shown that the Distress Thermometer (DT) can be useful in identify depression in cancer patients and, in conjunction with other measures, it has been shown to be effective in identifying symptoms of adjustment disorders (Akizuki et al., 2005; Hegel et al., 2008). This would include the designation of a cut score on the DT that is indicative of PTSS. Furthermore, researchers should consider the

construction of additional short-form measures that can identify PTSS without requiring cancer centers to expend additional resources.

Finally, this dissertation provided findings that support the possible relationship between treatment setting and the presentation of psychological distress. This is a new area of cancer research, but it builds upon findings that treatment setting impacts outcomes in other areas of healthcare (Flocke et al, 1998). These techniques should also be used to examine the effect of setting on other cancer-related mental health concerns. Specifically, studies should seek to examine the relationship between treatment setting and depression, PTSS, and substance use.

Recommendations for Future Practice

While this dissertation presents several interesting directions for future research, its aim was ultimately to help direct future behavioral health practices within oncology settings. This is an important consideration, as distress and PTSS have been shown to consistently worsen patient outcomes. The findings of this research can be directly applied to clinical practice in a number of ways. First, the recognition of factors which may place patients at risk can aid clinicians in early identification and serve as support for current distress screening procedures. This recognition should be tempered by the understanding that the DT is a screening tool, rather than a diagnostic instrument. This means that, although the DT may be particularly useful in determining which patients are experiencing distress, it may be less effective in determining which patients are not.

Secondly, better understanding the effect of clinic factors on distress can help provide context to clinicians' understanding of distress. From a more overall perspective, understanding the severe negative outcomes associated with distress and PTSS – including reduced treatment

adherence – could help foster increased cooperation between physicians, oncology social workers, nurses, psychologists, and other personnel.

Clinicians should also consider individual-level factors when tailoring assessment protocols. For example, this dissertation identified older age as a protective factor for psychological distress. Given this, clinical oncology staff might consider additional screening procedures for younger cancer patients. This could include increased scrutiny of instruments currently in use – such as the DT and the accompanying problem checklist. Problem areas identified by younger patients may need additional or proactive attention, even for those who do not report the most severe levels of distress.

Moreover, a better understanding of distress, PTSS, and posttraumatic growth (PTG) is an important step in improving patient outcomes. Clinicians should educate patients about these issues and direct them to appropriate resources, as needed. Given our current knowledge, patients with low levels of social support – or high levels of negative social support – may benefit from supportive services or therapeutic services. Additionally, clinicians should work with researchers to develop and implement interventions that promote protective factors and encourage PTG.

At the client level, understanding how common problems like distress and PTSS are within cancer populations may help de-stigmatize the conditions. Studies have shown that effective interventions exist for both distress and PTSS, but that early treatment is an important consideration in long-term outcomes. If patients feel more comfortable asking for help, it may be far more likely that they receive it, and consequently recover more quickly.

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