STARS

2017

Identification of Areas of Patient Need Using the Cancer Support Source Program

Emily Ross
University of Central Florida

STARS Citation

Showcase of Text, Archives, Research & Scholarship

IDENTIFICATION OF AREAS OF PATIENT NEED USING THE CANCER SUPPORT
SOURCE PROGRAM

by

EMILY JAYNE ROSS
B.S. University of Central Florida, 2015

A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Arts
in the Department of Psychology
in the College of Sciences
at the University of Central Florida
Orlando, Florida

Spring Term
2017

ABSTRACT

Understanding, screening, and providing resources for quality of life factors and psychosocial distress have become an important area of focus in cancer care. Negative consequences of poor quality of life and psychosocial distress have been widely studied in oncological research. The National Comprehensive Cancer Network, or NCCN, defines "psychosocial distress" as extending on 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" ("National Comprehensive Cancer Network," n.d.). Findings have indicated the significant impact of poor quality of life and psychosocial distress in the cancer patient population. Elevated levels of psychosocial distress increases the risk of developing depression, anxiety, immune suppression, and may lead to high levels of stress. Studies have also revealed associations between increased psychosocial distress levels, relapse, treatment and healing outcomes, and survival rates (Anderson, Kiecolt-Glaser, & Glaser, 1994; Spiegel & Nemeroff, 1997). Evidence also shows that heightened psychosocial distress negatively influences a patient's capability to adhere to their medical plan and treatment (Allison et al., 1995; Pirl et al., 2007; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Attending to these negative outcomes of psychosocial distress and providing supportive care is a crucial action of oncology practice today. The American College of Surgeons Commission on Cancer responded to the imperative of addressing psychosocial needs in cancer care by mandating national cancer centers for accreditation purposes to screen for psychosocial distress and provide appropriate referral and resources (Standard 3.2). UF Health Cancer Center – Orlando Health began psychosocial distress screening on January 1st, 2015 with the utilization

of the Web-based, HIPPA compliant, and action based Cancer Support Source Program. Patient data responses collected with the Cancer Support Source Program over the first calendar year of the implementation of the American College of Surgeons Commission on Cancer standards were analyzed for this research study.

A sample of 317 patient data responses was included to conduct an exploratory factor analysis (EFA) on the Cancer Support Source Program test items. Specifically, a Principal Component Analysis (PCA) with an oblique rotational procedure (Promax) was conducted on the resulting data set for interpretation. Factorial interpretation was made to ascertain latent dimensions in the Cancer Support Source Program. A five factor structure model was found with adequate discriminant and face validity. Factors were grouped by conceptual basis and item-loading composition: Distress, Treatment Management and Decisions, Lifestyle, Relationship, and Substance Use. These factors were collectively termed the Concern Subscales.

The Distress, Treatment Management and Decisions, and Lifestyle Factors were found to present the most psychometrically sound and internally consistent model. Further analysis was conducted to examine the resulting factorial structure model on four cancer location groups: breast, head and neck, lung, and gynecological cancer. Results displayed that no significant differences were found between cancer location groups and the five extracted factors. However, an ad hoc test (Tukey's HSD) revealed two significant differences between the Lifestyle Factor and cancer location groups at the $p < 0.05$ level. The Breast Cancer group's Lifestyle scores were higher than the Gynecologic Cancer group, and the Breast Cancer group scores were lower than the Lung Cancer group.

Additionally, the action scores were summed to examine correlation between the five extracted Concern Subscales. A high correlation was found, indicating that the action items in

the Cancer Support Source questionnaire correspond with the extracted Concern Subscales and do not need to undergo dimension reduction. Furthermore, a high correlation was also found with the extracted Distress Concern Subscale and the existing depression subscale in the Cancer Support Source Program.

Results indicated that the Cancer Support Source Program could indeed benefit from dimension reduction to ascertain more parsimonious areas of need presented by the cancer patient population. The 25 single-items in the Cancer Support Source questionnaire may inhibit the ability to indicate other concerns that may be expressed by the patient. By identifying the latent dimensions in this exploratory endeavor, we were able to demonstrate how the Cancer Support Source questionnaire could be refined to include easily scored Concern subscales to better identify areas of need for each individual patient that is screened for psychosocial distress. These findings provide an opportunity to impact patient care, opportunities for referral, and resources for cancer care in a hospital setting using this psychosocial distress screening instrument.

I dedicate my thesis to my father, Dr. Edward Allan Ross. I will always appreciate and be

grateful for his support and encouragement for me to complete and defend a thesis. He is my

inspiration to work hard and aspire for great achievements.

ACKNOWLEDGMENTS

I would like to acknowledge all those who have helped me with this academic endeavor. Thank you to my thesis chair, Dr. Jeffrey Cassisi for your guidance, wit, and support. Thank you to Dr. Diane Robinson for allowing me to use data from UF Health Cancer Center – Orlando Health and for your words of encouragement. Thank you to Dr. Bernard Jensen for your kindness and insight. Thank you to Chelsea Wiener for your encouragement throughout this study.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER ONE: INTRODUCTION

Quality of life and psychosocial issues have been identified as important areas of need in cancer care. Research has indicated that the presence of psychosocial distress has significant negative effects on an individual's quality of life and emotional, physical, and functional domains (Adler & Page, 2008; Carlson et al., 2004; & Institute of Medicine [IOM], 2007). The best ways to address this gap in oncology has been a topic for debate in the last two decades. The goal of high-quality integrated cancer care and the need for related support services has given rise to newly implemented accreditation standards and guidelines for oncological care. These guidelines specify the need to assess, measure, and address quality of life and psychosocial distress issues to optimize and prioritize patient treatment plans (American College of Surgeons Commission on Cancer, 2012).

Research exists on a variety of quality of life and psychosocial assessment tools to examine and measure potential areas for referrals, intervention, risk assessment, and supportive services for cancer patients (Vodermaier, Linden, & Siu, 2009). Furthermore, investigations of psychometric properties of these measures display strengths and limitations in their ability to identify and differentiate individuals at risk and in need of additional services (Buzaglo, Miller, Gayer, Morris, & Golant, 2013). However, psychometric research is limited on a newly created Web-based psychosocial distress screening program: the Cancer Support Source Program. An exploratory factor analysis (EFA) has the potential to extend the development and utility of this instrument. We will be investigating and addressing the empirical research question of the factor groupings of test items in the Cancer Support Source Program.

CHAPTER TWO: LITERATURE REVIEW

General Introduction to Quality of Life

Investigating the nature, conceptualization, and delineation of quality of life in health has been an empirical topic in research literature. The concept of quality of life encompasses multiple facets of an individual's life and becomes particularly relevant when analyzed in the context of health and, more specifically, a cancer diagnosis. Recently, there has been a heightened focus on quality of life (QOL) and health, research examining the impact of health related conditions on well-being in physical, social, cognitive, and emotional domains. Quality of life in patients with cancer plays a pivotal role in their treatment and management of cancer-related symptoms: it impacts physical, social, cognitive, and psychological domains. Some common physical symptoms patients experience are pain, fatigue, nausea, vomiting, and loss of appetite (Aaronson et al., 1993; Pandey, Dhungana, Twi, Byanju, & Khawas, 2015). Impairment in social functioning, occupational and financial disruptions, diminishment in cognitive ability, and psychosocial distress are also QOL indicators. Researchers are particularly cognizant of the impact QOL can have on a patient during their cancer experience, noting the significant role it plays on treatment outcomes, survival, and relapse rates. There is emerging evidence that improved QOL is associated with marginally extended survival rates (Pandey, Dhungana, Twi, Byanju, & Khawas, 2015). Research has shown quality of life factors play a direct role in how patients adhere to their treatment plan and make health care decisions. Stage of cancer, cancer-related symptoms, acceptance, and psychosocial distress are specific ways that the expression of cancer can impact QOL (Heydarnejad, Hassanpour, & Solati, 2011). Oncologists are also increasingly becoming more aware of addressing QOL factors in their patients. One study examined 260 oncologists and 80% agreed that QOL information should be obtained from their

patients (Bottomley, 2002). The importance of recognizing QOL in tandem with cancer care has

resulted in the formation and implementation of assessment measures to examine the impact

treatment has on cancer care. Evaluating quality of life and health-related issues can help

improve health care by "bridging boundaries between disciplines and between social, mental,

and medical services" (Centers for Disease Control and Prevention [CDC], 2016). This is also a

testament to the importance of integrative and multidisciplinary care in healthcare institutions.

An Overview of Psychosocial Distress

Assessing and understanding psychosocial distress has become a high priority area of

interest in cancer care and in the empirical oncologic literature. Recently, there has been a

greater emphasis on assessing in the treatment, management of care, and screening of patients

with cancer in hospital settings. While the topic of quality of life encompasses various

psychosocial distress symptoms, the National Comprehensive Cancer Network (NCCN) has

provided its own more specific definition of psychosocial distress. NCCN defines "psychosocial

distress" as extending on 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" ("National Comprehensive Cancer Network,"

n.d.). Furthermore, the NCCN emphasizes how psychosocial distress may impede the patient's

ability to effectively cope with a cancer diagnosis, physical cancer-related symptoms, and

treatment (Phillips, 2009). The prevalence and presence of psychosocial distress in the cancer

population has received considerable attention in recent years. It has been empirically recognized

as a stable and substantial problem, and findings indicate that approximately 30% to 40% of

cancer patients will endure elevated levels of psychosocial distress during their cancer course

(Carlson et al., 2004). One third of cancer survivors will experience persistent cancer-related fatigue and deteriorating mental health and well-being following a cancer diagnosis (Carlson et al., 2004; Costanzo, Ryff, Singer, & Burton, 2009; Escalante, Hesketh, & Savarese, 2013). Consequences of distress can cause disability across multiple life domains. Patients suffering from cancer and with lower quality of life may be more likely to engage in at-risk behaviors and less likely to adhere to health protection behaviors that may promote their well-being and reduce stress. Evidence also shows that heightened psychosocial distress negatively influences a patient's capability to adhere to their medical plan and treatment (Allison et al., 1995; Pirl et al., 2007; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Elevated levels of psychosocial distress also increase the risk of developing depression, anxiety, immune suppression, and may lead to high levels of stress. Chronic stress, a continuous activation of the sympathetic nervous system, leads to elevated levels of stress hormones such as norepinephrine, epinephrine, cortisol, and adrenaline (Moreno-Smith, Lutgendorf, & Sood, 2010).

Investigation of human and mice cells have indicated that elevated levels of norepinephrine may result in metastasis and angiogenesis (Smith, Lutgendorf, & Sood, 2010). One study reported that immune response is effected by dopamine levels: "…DA depletion decreases T-cell responses and promotes tumor growth in mice" (Basu, Dasgupta, & Chowdhury, 1995). Studies have also revealed associations between increased psychosocial distress levels, relapse, and survival rates (Spiegel & Nemeroff, 1997). Elevated psychosocial distress levels are also associated with increased length of hospital stays, re-hospitalization costs, a patient's desire for death, and morbidity and mortality rates (Allison et al., 1995; Pirl et al., 2007). These findings emphasize the importance of assessing stress as it relates to clinical outcomes in cancer care.

Furthermore, since there is a continuum of psychosocial distress, many patients with milder subclinical manifestations may not meet strict diagnostic criteria for a mental illness. However, these individuals are experiencing valid, tangible, and illness-related bio-psycho-social symptoms that would benefit from supportive services.

Institute of Medicine Report

Supportive care for patients with cancer is a crucial action of oncology practice today. This movement is traced back to the transformative report by the Institute of Medicine, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* in 2007. This empirically and medically based report provided recommendations and guidelines for addressing whole person, integrative, and collaborative care for patients with a cancer diagnosis (Adler & Page, 2008; Institute of Medicine [IOM], 2007). The Institute of Medicine report addressed psychological problems associated with cancer and illness, the negative consequences of these unmet needs, and standard of care recommendations for cancer treatment settings to ensure that the psychosocial needs of patients with cancer could be met and provided an opportunity for psychological services: *"...*good quality health care must attend to patients' psychosocial problems and provide services to enable them to better manage their illnesses and underlying health" (Institute of Medicine [IOM], 2007). Addressing psychosocial issues in cancer care has played a pivotal role in the advancement of oncology care since the release of this Institute of Medicine Report. Unfortunately, some physicians misjudge, undervalue, and overlook the significance of psychosocial distress in their oncological patients (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Keller et al., 2004; Merckaert et al., 2005). Findings indicated that less than 30% of patient-physician interactions discuss psychosocial concerns and needs (Rodriguez et al, 2010;

Taylor et al., 2011). Oncologist's clinical detection of depression has also been studied and findings have indicated a sensitivity rate of 29% and specificity of 85% (Fallowfield et al., 2001). The failure to detect and discuss these psychosocial concerns and problems in a patient suffering from a cancer diagnosis is a lost opportunity to provide them with well-rounded treatment and the ability to improve their overall quality of life. By thus targeting the "whole person" with high quality and multidisciplinary care, oncological services can improve treatment outcomes and potentially increase survival rates.

American College of Surgeons Commission on Cancer Standards

The recognition of psychosocial needs in oncology was further supported by the release of the American College of Surgeons (ACS), Commission on Cancer Standards 3.2 Psychosocial Distress Screening and 3.3 Survivorship Care Plan in 2015. The implementation date of these standards was January 1, 2015, and the imperative to meet that target for accreditation purposes motivated a new focus on patient-centered cancer care: one contingent on providing multidisciplinary approaches and comprehensive cancer care. These standards served as a foundation to effectuate psychosocial distress screening measures and survivorship care plans (SCPs) in accredited cancer sites (American College of Surgeons Commission on Cancer, 2012).

The Survivorship Care Plan (SCPs) Standards mandated the implementation of a "…comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment" (American College of Surgeons Commission on Cancer, 2012). The guidelines also recommended continued monitoring, documentation, and evaluation of the implementation process. The target behind SCPs are to better transition cancer survivors during their post treatment lives and to diminish negative outcomes that survivors experience, such as cancer-

related fatigue or psychosocial distress. Areas of needs addressed by SCPs may include relevant information on their cancer type, treatment, follow-up appointments, access to community resources, coordination and transition to a primary care provider (PCP), lifestyle changes, screenings, and prevention (Daudt et al., 2014).

A majority of PCPs see the value and importance of SCPs. Research has indicated that PCPs felt better prepared in their treatment of cancer survivors, particularly in regard to the comprehensive nature of SCPs and the improvement of care coordination with specialty oncologists (Shalom, Hahn, Casillas, & Ganz, 2011). Patient benefits from SCPs have also been researched, with recent studies finding that patients reported satisfaction in the usability, value, and knowledge provided in the SCPs (Faul et al., 2012; Sparague et al., 2013).

Despite much evidence and enthusiasm for implementation of the national standards, there have been some recent questions as to their benefit and efficacy. For example, patients reported continued confusion with coordination of care even following the implementation of SCPs (Sparague et al., 2013). Recent research is also finding credible and primary concerns with implementation of SCPs: increased burden and workload on health care clinics, sustainability and feasibility issues, and utility for patient care (Faul et al., 2012). Furthermore, emerging research has found that SCPs are ineffective; one systematic review on SCPs found no significant or measurable benefits on psychosocial distress and cancer outcomes (Brennan, Gormally, Butow, Boyle, & Spillane, 2014). One response to the controversial evidence of the inefficacy of SCPs was a revised template issued by the American Society of Clinical Oncology (ASCO) Survivorship Care Plan Working Group. The template minimized the "critical elements" required for SCP implementation and aimed to 1) increase adoption of SCP in clinical settings and 2) reduce resource load (Mayer, D.K., Birken, S.A., Check, D., & Chen, R.C.,

7

2015). However, diminished and questionable efficacy of SCPs on survivorship raises the empirical question of how successful the implementations of the ACS Commission on Cancer Standards can be in oncology care.

Psychosocial Distress Screening

The Psychosocial Distress Screening Standard specified and mandated that health professionals engage in psychosocial screening in cancer settings and, in turn, the opportunity for psychosocial support, services, and resources following cancer treatment. Supportive care can be more streamlined to directly address each individual case by screening patients with cancer for a range of psychological, physical, and social needs in tandem with their cancer treatment. The guidelines mandated that screening should be offered to the cancer patient at least once during a medical visit, with the exact timing of said medical consultation to be decided by the facility. If screening reveals a moderate to severe psychosocial distress, the program must provide additional investigation into how "psychological, behavioral, and social problems of the patient may interfere with their ability to participate fully in their health care and manage their illness and its consequences" ("National Comprehensive Cancer Network," n.d.). Most importantly, distress screening is tailored to target patients that are at high risk: those that present high levels of distress and are at an elevated risk for depression. Common distress screening tools include the NCCN Distress Thermometer (DT), Patient Health Questionnaire 9, Patient Health Questionnaire 2, Hospital Anxiety and Depression Scale, Beck Depression Inventory, and Brief Symptom Inventory (Vodermaier, Linden, & Siu, 2009). Monitoring cancer patient's distress throughout their treatment and cancer course allows for higher quality oncology care and the

opportunity for early intervention for psychosocial related problems. This may entail a referral, consultation, or opportunity for services.

The utilization of a standardized, validated instrument as a screening tool for cancer populations can have significant benefits: in the optimization of quality for patient-centered care; continuity of care; dissemination of information; optimization of treatment planning; identifying and discriminating risks; reduction of distress and barriers; devising cost-effective benefits; and providing a platform to address additional needs for services and interventions for the cancer patient. The optimal screening tool should assess the integrative needs of the patient, so as to provide a comprehensive assessment of all areas connected to their cancer diagnosis. This includes information about cancer, treatment, behavioral health changes, coping with financial situations, emotional consequences of cancer, proactive cancer management, occupational disruptions, practical problems, and familial/social impacts ("National Comprehensive Cancer Network," n.d.).

Since January 1, 2015, UF Health Cancer Center – Orlando Health has implemented routine and mandated psychosocial distress screening with the CancerSupportSource™ (version 2.0) Program. The first patient visit at the clinics is devoted to the patient's immediate medical needs, and on departure the psychological needs (support survey) are scheduled to commence at or prior to their return appointment. The patient may take the support survey online at home or onsite. An individualized "My Care Plan" is formulated from their responses and due to the Cancer Support Source Program's action-based mission, patients are then provided with opportunities for a broad range of referral and supportive services (Buzaglo, Miller, Gayer, Morris, & Golant, 2013). Support groups, counseling, psycho- education, pain-management,

nutrition, and physical exercise can be addressed at the Cancer Support Community, Integrative

Medicine Department at UF Health Cancer Center – Orlando Health.

Relevant Studies on the CSS Program: Efficacy and Implementation in Community Settings

The psychometric ability of the Cancer Support Source has been investigated with a

community based sample of 319 cancer survivors. High internal consistency was illustrated with

a Cronbach's alpha of 0.91. Additionally, test-retest reliability of ICC $\geq$ 0.75 was found to be

strong. The Cancer Support Source Program has also portrayed good concurrent validity and the

strong ability to differentiate clinically significant groups with the Distress Thermometer ($R(2) =$

$0.35, p < 0.001$), the Functional Assessment Scale of Cancer Therapy-General Well-Being Scale

($R(2) = 0.58, p < 0.001$), and the Center for Epidemiologic Studies Depression Scale ($R(2) =$

$0.48, p < 0.001$) (Miller et al., 2012).

An investigation of cancer survivors in a community-based Cancer Support Community

utilized the Cancer Support Source screening program. The study reported that most patients

experienced the highest level of distress within one year of their cancer diagnosis ($p = 0.011$) and

had a significant risk for depression ($p = 0.007$). During this time the highest concern of patients

with elevated levels of distress reported the desire to have discussions about their psychosocial

needs. Patients over a year from their cancer diagnosis had a depression risk of 45% and also

reported moderate to severe distress in areas such as worries about future, finances, and physical

exercise (Buzaglo et al., 2016).

Diverse racial-ethnic groups have also been evaluated utilizing the Cancer Support

Source screening program to examine unmet needs and highest distress levels. Findings

indicated that Latinos had the most significant levels of distress (p = .004). Areas of greatest

concern centered on treatment decisions and financial worries (Buzaglo et al., 2016).

A previous research study has utilized the Cancer Support Source Program to examine

test items that have the greatest discriminatory power by calculating the item discriminatory

index (IDI) using low ($\leq$ 4, n = 60) and high ($\geq$ 13, n = 59) distress respondents with 251 cancer

survivors at a community-based setting. Results showed that test items related to symptoms of

depression, exhaustion, fears, nervousness, functional problems, worries about the future, and

stressors (employment, academic, familial) had the greatest discriminatory power ($IDI \geq 0.8$).

Lowest discriminatory power was found with concerns associated with substance use,

transportation, nutrition, and suicidal ideation (Miller, Mullins, Onukwugha, Golant, & Buzaglo,

2014). The greatest discriminatory power found with the depression subscale is associated with

items related to pain, meaning in life, and treatment decisions (Buzaglo, Miller, Golant,

Longacre, & Kennedy, 2016). Findings such as these display the clinical importance of assessing

areas of need to devote appropriate resources in cancer care for supportive services, referral, pain

management, and assistance with treatment decisions.

Preliminary research has investigated the single, existing depression subscale in the

Cancer Support Source Program. This 4-item subscale is efficacious in screening and

discriminating for depression risk. The depression subscale items ask the test respondent how

concerned they are about feeling sad and/or depressed, feeling nervous or afraid, feeling lonely

or isolated, and feeling too tired to do the things you need or want to do (see Appendix C). The

validation study found a 91% sensitivity in identifying depression risk in community based

samples. Furthermore, rating five or more test items on a Likert scale 2 or greater will correctly

recognize a patient requiring further intervention and assessment for depression (Buzaglo,

Miller, Gayer, Morris, & Golant, 2013). Additionally, the Cancer Support Source Program has

been evaluated with the NCCN'S Distress Thermometer as a criterion. The validation study,

using the DT score greater than or equal to 4, found a 91% sensitivity and 49% specificity to

"somewhat to very seriously concerned with 5 or more" other test items.

Previous Multivariate Statistical Analyses on the Cancer Support Source Program

Multivariate regression analyses have previously been performed on Cancer Support

Source Program data. Specifically, procedures have examined descriptive concerns of patient

responses and delved into topics such as ethnic groups with highest distress and an examination

of depressive risk, time since cancer diagnosis, and distress levels.

A previous investigation on the Cancer Support Source Program performed a limited

regression analysis to identify ethnic groups (specifically Non-Hispanic White, African

American, and Latino) with the greatest psychosocial distress levels. The multivariate regression

analysis was adjusted for education, income, and age variables to examine the independent effect

of minority ethnic groups on psychosocial distress, depressive symptomatology test items, and

the chosen action to speak with a health professional to address concerns. Findings indicated the

Latino ethnic group had significantly higher levels of distress when compared to the Non-

Hispanic White group and at a higher risk for depression compared to the Non-Hispanic White

and African American groups. One implication of this study was the expressed need for factorial

statistical analysis: "…future research should investigate factors that impact distress" (Buzaglo,

Miller, Kennedy, Longacre, & Golant, 2016).

An additional research study on the Cancer Support Source Program also utilized a

multivariate regression analysis to identify and delineate unmet psychosocial concerns of

patients at varying points of cancer diagnosis. The adjusted regression analysis examined age, distress levels, specific concerns, and the screening response to speak to a health professional about their concerns. This study also expressed a desire for future investigative procedures of factors within the test-items: "…identify factors that predict those at greatest risk for ongoing and persistent distress" (Buzaglo et al., 2016).

To date, there have been no explorations on subgroupings and subscales of the test items in the Cancer Support Source Program, such as physical, psychosocial, and practical. The purpose of this study is to determine whether there are underlying relationships between the test items in the Cancer Support Source Program, and to thus identify domains of need that can be the basis of improved care for patients with cancer. Individual test items in the Cancer Support Source Program are helpful, but there may be an additional benefit to grouping and identifying patterns of test items to thereby direct and prioritize cancer care.

CHAPTER THREE: METHODOLOGY

Measure

The Cancer Support Source Program has demonstrated validity and reliability in psychometric studies. This computer and Web-based program contains 25-items and is time-limited and compliant with The Health Insurance Portability and Accountability Act (HIPPA). The Cancer Support Source Program is also easily accessible for patients, where they can complete the survey onsite at their medical visit on a tablet or online at home (Buzaglo, Miller, Kennedy, Longacre, & Golant, 2016). Test items are formulated on a 5-point Likert scale and ask respondents to rate their current concern severity level from 1(not at all) to 5(very seriously). The Cancer Support Source Program test items target multiple needs and symptoms of the patients, and include: nutrition, transportation, sexual problems, sleep, fatigue, emotional coping, worries, exercise, body image, mobility, treatment, and finances and their desire for assistance in a brief, concise, and timely manner (see Appendix C). Furthermore, the Cancer Support Source Program contains companion items which allow the patient to choose the level of action and need for services to address their distress: talk to a health professional, receive printed resources, or other information available as online materials (Vodermaier, Linden, & Siu, 2009).

Participants

Participant data was obtained from an archival data set taken from the Cancer Support Source Program implemented across the UF Health Cancer Center – Orlando Health clinics by the Integrative Medicine Department. UF Health Cancer Center – Orlando Health has cemented itself in excellence: it is in the top five national academic cancer sites, is the largest and most comprehensive cancer program in Florida, and has Commission on Cancer accreditation.

Furthermore, the UF Health Cancer Center – Orlando Health is designated by the state as the only cancer center of excellence in Central Florida. There have been no investigative procedures performed on Cancer Support Source data housed at a hospital setting, as the primary and prevalent usage of the Cancer Support Source Program has been in community and stand-alone sites.

The research study was exempted by the Institutional Review Board at UF Health Cancer Center – Orlando Health. An approval letter confirming this exemption can be found in Appendix A. Additionally, a letter from UCF's Institutional Review Board can be found in Appendix B. No identifying PHI was utilized in this research endeavor. The original archival data set was approximately 1000 patient data entries. The N of 1000 was cleaned for data analysis and the resulting N was comprised of 719 patient data entries. For the purpose of this study, the data set was split into two randomized subsamples (Group 1, N = 336; and Group 2, N = 383), and an analysis of one randomized sample group (Group 1, N = 336) was used in this exploratory research endeavor. The second randomized sample group (Group 2, N = 383) of the Cancer Support Source Program patient data entries will be used in a future study (Confirmatory Factor Analysis). The exploratory analysis (EFA) performed in this research study will be a template for future procedures and statistical analyses on the test items and patient data responses from the Cancer Support Source Program. Only completed, online, or onsite distress information from January 1, 2015 to December 31, 2015 was utilized and analyzed for this research study. This patient data set included cancer location, patient gender, and responses on the test items in the Cancer Support Source Program.

Participants completed the distress screening, as this is a standard of clinical care, and a retrospective study examining archival data. As such, the completion of the distress screening

would represent the wish of the subject to participate in the best interest of their clinical care, and this data will be used to improve this care.

Justification of Factorial Techniques

For the purpose of this study, an exploratory factor analysis (EFA) was conducted to analyze underlying and inter-correlated factor groupings of the test items in the Cancer Support Source Program. The EFA statistical technique is appropriate due to the investigative nature of this study: to determine and extract groupings of test items to understand patient areas of need in cancer care targeted by the Cancer Support Source Program. There are neither prior assumptions nor expectations on the theoretical latent dimensions and constructs of the test items in the Cancer Support Source Program. This was an exploratory and heuristic endeavor.

The implementation date of the American College of Surgeons Commission on Cancer Standards 3.2 at UF Health Cancer Center – Orlando Health utilizing the Cancer Support Source Program began on January 1, 2015. Therefore, data analysis began with 336 archived patients over a calendar year: starting on January 1, 2015 to December 31, 2015. Research findings delineate varying recommendations on sample sizes for an EFA. One guideline advised having at least a sample size of 300 and another study reported that a suitable sample size is greater than 100 (Hair, Anderson, Tatham, & Black, 1995; Tabachnick & Fidell, 2007). Researchers Comrey and Lee categorize sample sizes of "…100 as poor, 200 as fair, 300 as good, 500 as very good, and 1000 or more as excellent…" (Comrey, 1973; Williams, Onsman, & Brown, 2014). Therefore, it can be argued that the data set utilized for this analysis is large enough to adequately perform an EFA.

Sample variable ratio (*N:p*) recommendations have been evaluated in exploratory factor analysis research findings and guidelines; with ambiguity concerning what sample variable ratio is optimal. Ranges of sample variable ratios include: "3:1, 6:1, 10:1, 15:1, or 20:1" (Comrey, 1973; Everitt, 1975; Gorsuch, 1983; Guadagnoli & Velicer, 1988; Pett, Lackey, & Sullivan, 2003; Sapnas & Keller, 2002; Swisher, Beckstead, & Bebeau, 2004; Tabachnick & Fidell, 2007; Thompson, 2004). One previous research study examined the influence of sample size on a data set's ability to produce reliable factor solutions (Costello & Osborne, 2005). Findings indicated that 70% of sample variable ratio data set of 20:1 produced reliable and statistically meaningful factor solutions and resulted in less misclassification of factors (Costello & Osborne, 2005). The sample variable ratio is approximately 13:1. Therefore, the sample variable ratio is justified to be adequate for the multivariate statistical analysis and enhances the probability of extracting meaningful and interpretable factor solutions (Stevens, 2002).

The Cancer Support Source Program archival data set contains 25 test items in which an extraction of factor groupings was made from the sample size of 336. The two randomized subsamples (Group 1, N = 336; and Group 2, N = 383) were randomized utilizing demographic variables, a *p* = .1, and repeated trials to uphold the randomized integrity of the two subsamples. Cross validation, Eigenvalues, scree plots, and a rotational method procedure was used to extract a factor structure of the test-items and to reveal test items loading on the same factors of these two sample groups (see Chapter Four: Results).

Research literature on EFAs promote a variety of approaches to factor extraction; these include: principle components analysis (PCA), principal axis factoring (PAF), alpha factoring, maximum likelihood, un-weighted least squares, generalized least squares, image factoring, and

canonical (Tabachnick & Fidell, 2007; Thompson, 2004). The factors were extracted utilizing the PCA method.

Findings have indicated disparate opinions on the statistical integrity of utilizing a PCA for a factor analysis. Some statistical research discusses that conducting a PCA extracts components and not factors, thereby concluding that it is not a true factor analysis procedure (Tabachnick & Fidell, 2007). However, many researchers have determined that utilizing a PCA is synonymous to other factorial extraction statistical techniques and will produce nearly analogous factor loadings. Our theoretical reasoning behind utilizing a PCA is due to its data reduction ability and its inclusion of both shared and unique variances (Costello & Osborne, 2005). A PCA analysis also assumes redundancy within variables; hence there is a possibility that variables are correlated and measuring a similar construct, i.e. areas of need in the Cancer Support Source Program test items. In this regard, we were able to reduce the variables in our data set to a more parsimonious number of principal components. Furthermore, a PCA analysis does not take into account a prior notion of underlying latent variables, which aligns with the exploratory research question.

Factor extraction was based upon multiple criteria, as it is recommended "no single criteria should be assumed to determine factor extraction" (Costello & Osborne, 2005). Therefore, an analysis of both the Scree plot and eigenvalues was made to determine the amount of factor solutions to retain. The utilization of a Scree Plot with eigenvalues resulted in a visual representation of the possible number of factor solutions (point of diminished return or elbow). Research has demonstrated that a Scree Plot is reliable to use on data sets with a sample size of 200 or above. Thereby we can justify that the subsample group (N = 336) exemplified an adequate sample size to feasibly use a Scree Plot. The "Total Variance Explained" in the SPSS

output and the natural break of the Scree Plot curve was examined to determine retainable factors. Statistical recommendations emphasize that only rotated and extracted data are meaningful for interpretation, thus an evaluation of eigenvalues and variances was made after a rotational method has been performed. Specifically, this interpretation was made using the SPSS output Total Variance Explained (see Table 1) (Yong & Pearce, 2013).

Multiple analyses were run to diminish possibly subjectivity of this visual inspection test: this will allow us to retain factors in a manual fashion and to objectively conclude the numerical quantity of factors in the data set sample groups (Costello & Osborne, 2005). Data extraction will be supported by these multiple repeated procedures due to the complex, dynamic nature of interpreting factorial analyses results. Therefore, multiple approaches to our factor extraction were utilized to 1) avoid subjectivity in interpretation of results and 2) avoid possible errors or oversights and 3) justify the quantity of meaningful factors within our data set.

A rotational method was utilized to "…maximize high item loadings and minimize low item loadings" (Williams, Onsman, & Brown, 2014) to combat the possibility of specific test items in the Cancer Support Source Program relating to more than one factor grouping (Williams, Onsman, & Brown, 2014). A factorial rotational method is useful in initial factor and dimension extraction because it identifies "simple and interpretable factors" (Yaremko, Harari, Harrison, & Lynn, 1986).

Research findings indicate that oblique and orthogonal rotational methods may produce nearly identical and conceptually similar results (Costello & Osborne, 2005). However, statistical literature demonstrates that the selection of a specific rotational method is contingent on the nature of factors being correlated (oblique rotational method) or uncorrelated (orthogonal rotational method). Findings recommend to initially employ an oblique rotational method to

determine the optimal rotational procedure to perform on the data set. A manual entry input of the hypothesized desired number of factors with an oblique rotational method will result in a degree of correlation within the data set. Hence, the notion here is to guide researchers in determining the necessity of performing an orthogonal rotation on the data set (Brown, 2009).This method was employed to analyze the degree of correlation in our data set and to guide our choice of a specific rotational method. As per recommended by statistical researchers Tabachnick and Fiddell, an analysis of the degree of correlation within our data set was made. Correlations around .32 or above were interpreted as merit for the utilization and justification of an oblique rotational analysis, due to the 10% variance overlap. However, if the data set had not contained correlational factors, then an orthogonal rotational method in our statistical analysis would have been pursued for final factorial interpretation (Tabachnick & Fidell, 2007). This methodology was utilized to enhance the credibility and feasibility of our decision to use the specific rotational method in this statistical analysis.

Statistical findings were interpreted in a meaningful and theoretical fashion. High factor loadings were analyzed to adequately identify the strength of relationships within test items to group test items into factors. Additionally, an identification of low and zero factor loadings with minimal relationship strength confirmed and justified our factor groupings. A cut-off of .32, two-tailed alpha level of 0.1, and the rotated factorial procedure was used to make statistically meaningful and reliable interpretations of the factor loadings (Tabachnick & Fidell, 2007; Yong & Pearce, 2013).

There is a definite paucity in the Cancer Support Source Program literature of a multivariate statistical analysis on the specific test items. The key conceptual basis here is to gain further knowledge on the nature of the factors within these test items. The statistical results will

demonstrate 1) grouping test items into specific areas of need utilizing factor extraction, 2)

display specific descriptive findings on factors scores, and 3) will be a basis for improvement in

the Cancer Support Source Program. The findings from this study will also disseminate vital

information on factor groupings within the test items; which will generate future research on

underlying subscales and hence provides a foundation for the confirmatory factor analyses

procedure (CFA). Conducting an EFA on the Cancer Support Source Program test items

provides meaningful and relevant information on psychosocial distress screening results to

differentiate patient areas of need in a more parsimonious and valid fashion. The results of our

multivariate statistical analysis (see Chapter 4: Results) can be the basis to improve the

interpretation of the Cancer Support Program screening results to better prioritize and improve

clinical care by determining areas of need (factors) within the test items.

CHAPTER FOUR: PROCEDURE

The total data set of 719 was randomly split into two subsamples (Group 1, N = 336; and Group 2, N = 383). The first sample group was used in this study, while the second sample group was retained for future research to cross-validate the findings presented here. Univariate outliers were retained in the data set due to the research interest of assessing respondents with extreme responses to different items.

The two sample groups were compared to ensure that they were not significantly different on the available measures and to determine if the random split was successful. Chi square tests were conducted to determine if any significant differences between the two randomized sample groups existed in the categorical data. Indeed, no significant differences were found between the two randomized groups concerning the frequency of gender χ^2 (2, N = 719) = 2.65, p =.27, depression risk χ^2 (1, N = 719) = 0.00, p =.99, and cancer location χ^2 (11, N = 719) = 10.96, p =.45. Next the ordinal items from the two randomized groups were compared. Independent samples Mann-Whitney U Tests were conducted on the 25 items from Cancer Support Source questionnaire for the two randomized sample groups. Results from the individual Mann Whitney U tests did not find significant differences between groups on any of the 25 items on the Cancer Support Source questionnaire. Since no evidence for differences between the groups existed on any categorical or ordinal measure, the randomization was deemed successful. The subsequent analyses and narrative for this thesis is based on the first sample group. The second sample group will be utilized in future efforts to cross validate the findings obtained here with Confirmatory Factor Analysis (CFA) procedures.

Missing Data

Initially, there were 336 patients in the group one sample data set. This data set was reviewed for missing data. Patients with three or more item non-responses were eliminated ($N =$ 19). Those with two, or less missing responses ($N = 58$) were retained in data set and mean replacement was used for the missing items. Therefore, the final data set used here included 317 patients. The top five most common missing responses were the items: "finding meaning and/or purpose in life" ($n = 12$), "managing side effects of treatment" ($n = 10$), "intimacy, sexuality and/or fertility" ($n = 10$), "feeling irritable" ($n = 11$), and "pain or physical discomfort" ($n = 11$).

Statistical Methods

All statistical analyses were conducted in SPSS Version 23. Exploratory factor analyses (EFA) were conducted on the data set as the primary statistical analytical procedures. The specific EFA chosen was Principal Component Analysis (PCA). Specifically, Tabachnick and Fidell (2013) recommend using a PCA to discover latent dimensions within a set of variables in a descriptive manner, as is consistent with the aims of the current study. Two PCA's were conducted to ascertain the stability of the results. In the first PCA an oblique rotational procedure (Promax) was conducted and in the second an orthogonal rotational procedure (Varimax) was used. The Promax rotation is indicated when the factors are likely to correlate, it is expected that the factors extracted in this current study would exhibit correlation due to their relation with distress. Furthermore, Promax rotation is recommended due to its conceptual simplicity, expedient nature with larger data sets, and its ability to achieve a simple structure. In comparison, the Varimax rotation is recommended for non-correlation driven factors, offers simplicity in interpretation, and allows for maximization of the variance of the factor loadings

(Abdi & Williams, 2010). The factor solutions obtained by the two approaches revealed few differences in the factor structure and resulting item loadings as determined by the variance accounted for and the Eigenvalues. Since the factors on the Cancer Support Questionnaire are expected to correlate, the final factor solution is presented and interpreted with the Promax rotation.

Results

The appropriateness of the data set for EFA was examined in several ways. Tabachnick and Fidell (2013) recommend that a minimum value for the KMO index (ranging from 0-1) of 0.6 to conduct an adequate factor analysis. The KMO index for this data set was 0.93, which indicates the data set is well-suited for factor analytic analysis. Bartlett's Test of Sphericity was significant ($\chi^2 (300) = 3620.54$, $p < .05$), therefore the null hypothesis that the correlation matrix is an identity matrix was rejected, also indicating that the dimensions of the data set can be reduced (Appendix E). Additionally, all diagonal items in the anti-image correlation matrix met the recommended criteria of above 0.5, indicating that all items could be retained for factor analysis. The extracted factors were evaluated to determine the percentage of variance, e.g. communalities. The recommended minimum value for communalities (0.30-0.40) was met, confirming that the data set test items had adequate shared common variance and relation with extracted factors and could all be retained for subsequent analysis (see Appendix G). Tabachnick and Fidell (2013) criteria also suggest that an adequate factor model will present with less than 50% of non-redundant residuals with an absolute value greater than 0.5, which is confirmed in this data set as 33.0% non-redundant residuals were found with absolute values greater than 0.5.

The PCA with Promax rotation produced five extracted factors with Eigenvalues (greater than 1). The first factor explained 38.17% of the variance, the second factor 5.65% of the variance, the third factor accounted for 5.52 % of the variance, the fourth factor accounted for 4.66% of the variance, and the fifth factor accounted for 4.21% of the variance. The five extracted factors accounted for 58.20% of the cumulative variance (see Table 1).

Table 1 *Total Variance Explained with Principal Component Analysis with Promax Rotation with Kaiser Normalization*

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotated Sum of Squared Loadings
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	9.54	38.17	38.17	9.54	38.17	38.17	8.12
2	1.41	5.65	43.82	1.41	5.65	43.82	6.83
3	1.38	5.52	49.33	1.38	5.52	49.33	5.75
4	1.17	4.66	53.99	1.17	4.66	53.99	3.34
5	1.05	4.21	58.20	1.05	4.21	58.20	1.10
6	.93	3.72	61.92				
7	.88	3.51	65.42				
8	.79	3.18	68.60				
9	.77	3.06	71.66				
10	.75	3.00	74.66				
11	.66	2.65	77.31				
12	.65	2.58	79.89				
13	.60	2.39	82.28				
14	.55	2.19	84.47				
15	.53	2.11	86.58				
16	.49	1.97	88.54				
17	.45	1.79	90.34				
18	.43	1.70	92.04				
19	.37	1.46	93.50				
20	.35	1.39	94.89				
21	.32	1.28	96.17				
22	.28	1.11	97.28				
23	.26	1.05	98.33				
24	.22	.89	99.21				
25	.20	.79	100.00				

Note. When components are correlated, sums of squared loadings cannot be added to obtain a total variance.

The structure matrix suggested five factors for interpretation (see Table 2). The structure matrix was the primary matrix utilized for interpretation due to its ability to find correlations between factors and variables (Beavers et al., 2013; Rietveld & Van Hout, 1993). However, the

pattern matrix was also consulted to reveal replicability and consistency across factor loadings within the extracted factors. A visual inspection of the structure matrix indicated high factor loadings for five factors[1]: Factor 1 (Distress) 9 items, Factor 2 (Treatment Decisions and Management) 8 items, Factor 3 (Lifestyle) 5 items, Factor 4 (Relationship) 2 items, and Factor 5 (Substance Use) 1 item.

Table 2 *Structure Matrix: Factor loadings and Communalities Based on a Principal Component Analysis with Promax with Kaiser Normalization Rotation for 25 items from the Cancer Support Source Questionnaire (N = 317)*

Item	Component				
	1	2	3	4	5
1	.320	**.550**	.537	.379	-.196
2	**.660**	.311	.507	.425	.154
3	.359	.283	**.808**	.133	.189
4	.339	**.633**	.466	.195	.181
5	.538	.320	**.570**	.358	.118
6	.639	**.657**	.402	.483	.024
7	**.864**	.443	.477	.378	.032
8	.332	**.558**	.205	.136	.405
9	**.654**	.482	.650	.060	.184
10	.557	**.601**	.399	.389	-.199
11	**.854**	.473	.413	.251	-.028
12	**.840**	.556	.462	.234	-.023
13	.553	**.754**	.320	.184	.110
14	.369	.442	.255	**.796**	-.051
15	**.733**	.418	.412	.449	.124
16	**.514**	.485	.457	.317	.141
17	.310	.188	.196	**.794**	.134
18	.629	.411	**.709**	.220	.022
19	.691	**.734**	.407	.149	-.017
20	**.689**	.588	.348	.304	.127
21	.362	.473	**.603**	.215	-.380
22	.488	.647	**.728**	.303	-.225
23	.199	.166	.165	.160	**.655**
24	.341	**.707**	.340	.305	-.087
25	**.627**	.595	.444	.375	.030

---

[1] The factor labels are based on visual inspection of the highest loading items in a factor.

A visual inspection of the Scree Plot indicated a leveling off (the elbow) of Eigenvalues after five extracted factors, however visual interpretation of the graph was difficult since the first extracted factor explained a disproportional amount of the variability in the data set (see Figure 1). Due to the subjective nature of interpreting the Scree Plots, and since factors 2 through 5 explained a significant amount of variance and were theoretically coherent, emphasis was placed on the structure and pattern matrix in order to determine the appropriate number of extracted factors.
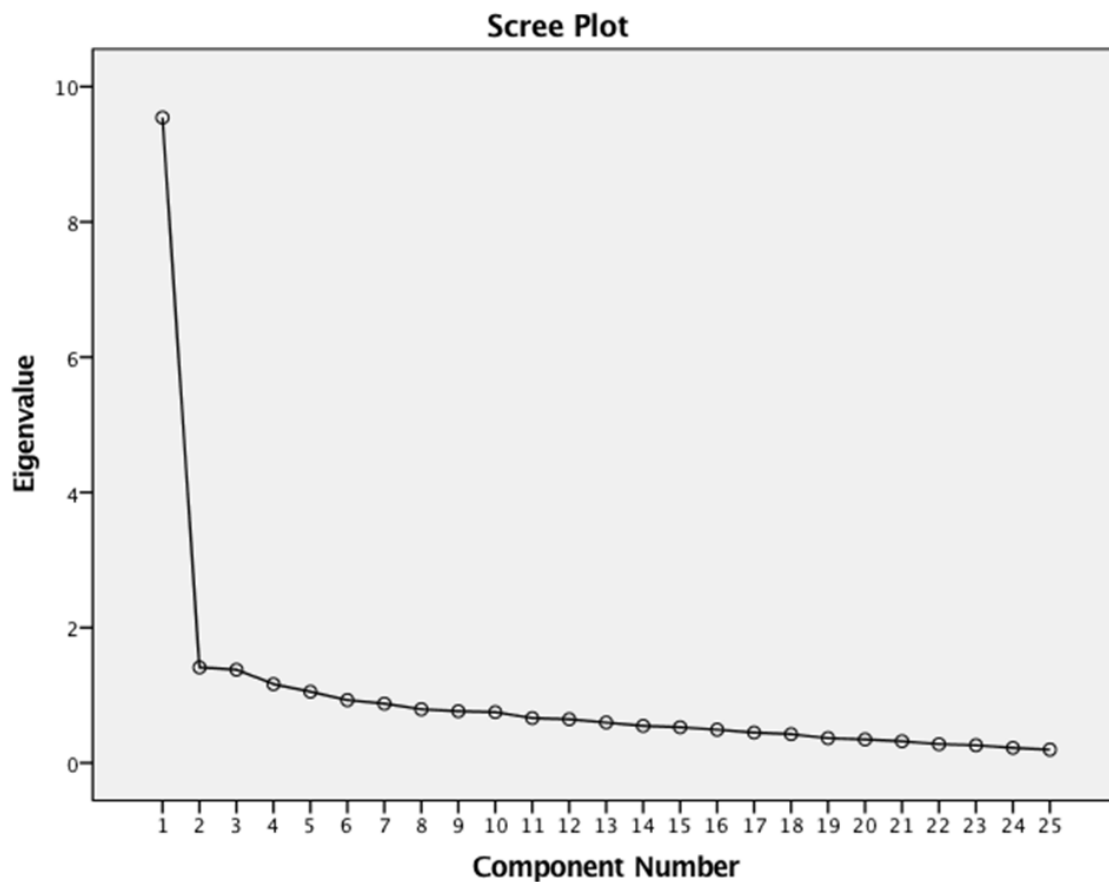
Figure 1 *Scree Plot of Eigenvalues and Component Numbers*

Nature of Factors

Two methods were used to demonstrate adequate discriminant validity for the five extracted factors. First, the structure matrix was evaluated to extrapolate variables loading significantly on one factor and to ensure that no significant cross-loadings were occurring (see Table 2). Second, the component correlation matrix was examined to ensure that factor correlation did not exceed 0.7 (see Table 3). Sufficient face validity was found indicating that items loading on the same factor made conceptual sense. For example, items loading in the Treatment Decisions and Management Factor centered on communicating with your doctor, transportation, managing side effects of treatment (such as body image), decisions about treatment, and finding reliable information about treatment.

Table 3 *Correlations Among Components with Principal Component Analysis with Promax Rotation with Kaiser Normalization*

Component	1	2	3	4
2	.59			
3	.54	.50		
4	.38	.34	.31	
5	.09	-.07	-.03	-.04

Internal consistency of the extracted factors was examined by conducting a reliability analysis with Cronbach's Alpha. The Distress Factor had a Cronbach's Alpha of 0.89, the Treatment Management and Decisions Factor had a Cronbach's Alpha of 0.83, the Lifestyle Factor had a Cronbach's Alpha of 0.76 and the Relationship factor had a Cronbach's Alpha of 0.62. A Cronbach's Alpha for the Substance Use Factor could not be computed because it was a

single-item factor. The Cronbach's Alpha for the first three factors would be classified as

acceptable values for a reliability coefficient (George & Mallery, 2003; Tavakol & Dennick,

2011).

Each factor was treated as a subscale score for each patient by totaling the item scores

and dividing by the number of items (with the exception of the last factor which only had a

single item). These factors were computed into subscales and are collectively called the Concern

Subscales. Table 4 presents the items for each subscale on the Cancer Support Questionnaire.

Table 5 presents the correlations between the 5 subscale scores.

Table 4 *Cancer Support Source Item Composition for Five Concern Subscales*

Scale	Item Number on Cancer Support Source Questionnaire
Distress	2, 7, 9, 11, 12, 15, 16, 20, 25
Treatment Management and Decisions	1, 4, 6, 8, 10, 13, 19, 24
Lifestyle	3, 5, 18, 21, 22
Relationship	14, 17
Substance Use	23

Note. Cancer Support Source Questionnaire test items can be found in Appendix C.

Table 5 *Pearson Correlations Among Five Concern Subscales of Cancer Support Source Questionnaire*

	Distress	Treatment	Lifestyle	Relationship
Treatment	$.74^{**}$			
Lifestyle	$.71^{**}$	$.65^{**}$		
Relationship	$.42^{**}$	$.43^{**}$	$.33^{**}$	
Substance Use	$.23^{**}$	$.21^{**}$	$.14^{*}$	$.17^{**}$

Note. **. Correlation is significant at the 0.01 level (2-tailed). *. Correlation is significant at the 0.05 level (2-tailed).

Comparing Cancer Support Source Questionnaire Subscales by Cancer Location

Patients were assigned to cancer location groups. Patients fell into one of 12 cancer classifications: breast, blood, lung, head and neck, gynecologic, gastrointestinal, skin, prostate, liver, brain and spine, pancreatic, and multiple locations. Cancer groups which had an *N* greater than 20 were retained to compare Cancer Support Group Questionnaire Concern subscales by cancer location. These four groups were breast, head and neck, lung, and gynecologic cancer. Table 6 displays the subscale scores by these 4 cancer locations.

Table 6 *Descriptive Statistics for Cancer Support Source Questionnaire Concern Subscales by Cancer Location*

Cancer Location M(SD)	Factor Subscale				
	Distress	Treatment Management and Decisions	Lifestyle	Relationship	Substance Use
Breast (N = 116)	2.21 (.96)	2.28 (.90)	2.18 (.92)	1.52 (.92)	1.25 (.84)
Lung (N =21)	2.56 (.97)	2.66 (.96)	2.74 (.87)	1.38 (.69)	1.71 (1.38)
Head and Neck (N = 51)	2.23 (.88)	2.27 (.87)	2.20 (.87)	1.55 (.84)	1.27 (.78)
Gynecologic (N = 45)	2.19 (.95)	2.12 (.76)	2.11 (.91)	1.20 (.40)	1.41 (1.08)

Note. Standard deviations appear in parentheses below means.

The scores on the five subscales of the Cancer Support Source Questionnaire for these four cancer groups were compared with MANOVA. No significant multivariate differences were found by group, Wilk's Lambda $F(15, 621) = 1.55$, $p < .08$, $\eta^2 = .03$. Univariate tests of effects were conducted separately for each subscale by group and revealed that the Lifestyle subscale score approached significance, $F(3) = 2.578$, $p < .06$, $\eta^2 = .03$. Ad hoc tests were then conducted to identify where the trends were for the cancer groups to differ. Indeed, Tukey's HSD revealed two significant differences at the $p < 0.05$ level. The Breast Cancer group's Lifestyle scores were higher than the Gynecologic Cancer group, and the Breast Cancer group scores were lower than the Lung Cancer group. Figure 2 presents the Lifestyle scores by group.
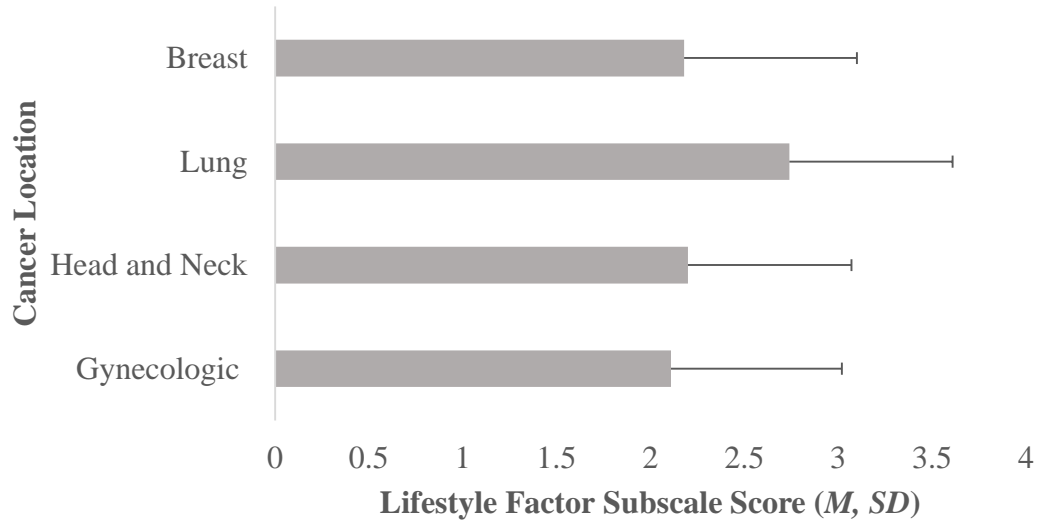
Figure 2 *Bar graph of lifestyle subscale by cancer locations breast, lung, head and neck, and gynecologic*

Comparing Cancer Support Source Questionnaire Subscale Action Items by Cancer Location

On the Cancer Support Source Questionnaire there is a column of companion items corresponding to the concern items asking the patient to choose the level of action they wish to receive (see Appendix C). These questions are called "Action" items. These companion questions have the header "Please let us know how we can help you..." The three response options for each item in this column are: "Have a staff person talk with you," "Provide you additional information," or "No action needed." Thus for each item identifying a specific concern of the patient, they can indicate whether they require additional personalized attention on that topic.

In order to develop a scoring system for the four subscales with two or more action items, each occurrence of a response indicating no action was required was counted as a "0." Secondly, each occurrence of a response indicating wanting more information was counted as a "1." Lastly,

each occurrence of a response indicating wanting a staff person to talk with them was counted as a "2." These scores were then summed within subscales and represented the "Action" score for that subscale. The mean and standard deviation of this count by Cancer Location is presented in Table 7.

Table 7 *Mean Action Subscale Scores for Cancer Locations Breast, Lung, Head and Neck, and Gynecologic*

| Cancer Location *M(SD)* | Action Scores by Subscale | | | |
	Distress	Treatment Management and Decisions	Lifestyle	Relationship
Breast (N = 116)	3.41 (4.30)	3.28 (3.53)	2.04 (2.28)	0.37 (.87)
Lung (N =21)	5.14 (4.79)	4.86 (3.76)	2.71 (2.59)	0.10 (.30)
Head and Neck (N = 51)	2.69 (3.23)	2.65 (3.52)	1.49 (1.87)	0.20 (.53)
Gynecologic (N = 45)	3.04 (4.24)	2.78 (3.33)	1.89 (2.17)	.11 (.32)
Total	3.34 (4.15)	3.18 (3.54)	1.95 (2.22)	0.26 (.69)

Note. Standard deviations appear in parentheses below means.

Next the four Cancer Support Source Subscale Concern Scores were correlated with Subscale Action Scores. These are presented in Table 8.

Table 8 *Pearson Correlation between Cancer Support Source Subscale Concern Scores with Subscale Action Scores*

	Distress Action Score	Treatment Management and Decisions Action Score	Lifestyle Action Score	Relationship Action Score	Distress Concern Score	Treatment Management and Decisions Concern Score	Lifestyle Concern Score
Treatment Management and Decisions Action Score	.86**						
Lifestyle Action Score	.77**	.76**					
Relationship Action Score	.41**	.42**	.33**				
Distress Concern Score	.78**	.62**	.59**	.34**			
Treatment Management and Decisions Concern Score	.68**	.79**	.61**	.39**	.75**		
Lifestyle Concern Score	.62**	.56**	.73**	.27**	.74**	.66**	
Relationship Concern Score	.28**	.28**	.23**	.80**	.41**	.39**	.31**

Note. **. Correlation is significant at the 0.01 level (2-tailed).

The four Subscale Action Scores for each of the Cancer Location groups were contrasted using separate univariate ANOVAs and no significant differences were obtained.

Comparing Depression Subscale with Distress Concern Subscale

The item loadings on the Distress Concern Subscale were investigated to ascertain if these items correspond to the 4-items that comprise the existing depression subscale: 7, 11, 15, and 18(see Appendix C). The Distress Concern Subscale did indeed contain three of the items that are contained in the depression subscale: 7, 11, and 15. These three items also demonstrated

the highest item loadings on the Distress Concern Subscale with item loadings .864, .854, and .744, respectively. A high correlation was found between the depression subscale and the Distress Concern Subscale, $r(315) = .91$, $p < .01$. A one-way ANOVA was conducted for the four cancer location groups (breast, lung, head and neck, and gynecologic cancer) and the depression subscale. No significant differences were found, $F(3, 229) = 1.48$, $p = .22$.

CHAPTER 5: DISCUSSION

The EFA (Principal Component Analysis) conducted on the Cancer Support Source Program test items yielded a five factor structure solution, adequate psychometric properties, and the promise of clinical utility. Specifically, two EFA's (one performed with an oblique rotation and one with an orthogonal rotation) were conducted to replicate the solution across procedures. Additionally, both the structure and pattern matrix were interpreted for resulting item-loadings to demonstrate that factor extraction and dimension composition were consistent.

The PCA, conducted with Promax rotational procedure was used as the basis for interpretation. It yielded five factors with eigenvalues greater than 1 which were retained and extracted. The five factors were labeled using the highest loading item on that factor as a guide. Items on each factor were coherent and the interpretation was straightforward indicating good face validity. These factors were computed into subscales and are termed the Concern subscales. Each factor was labeled as follows: Distress (Factor 1), Treatment Management and Decisions (Factor 2), Lifestyle (Factor 3), Relationship (Factor 4), and Substance Use (Factor 5). Due to the few items loading on the Relationship factor and Substance Use factor (2-item and 1-item loadings respectively), only the Distress, Treatment Management and Decisions, and Lifestyle Factors could be evaluated for internal consistency with Cronbach's Alpha. The internal reliability of those 3 subscales was found to be good to very good.

A further analysis of the five extracted factors indicated that the first factor, Distress Factor, accounted for 38.17% of the variance and the greatest number of high item loadings (9-item loadings). In comparison, the Treatment Management and Decisions Factor (8-item loadings) accounted for 5.65% of the variance, the Lifestyle Factor (5-item loadings) accounted

for 5.52% of the variance, the Relationship Factor (2-item loadings) accounted for 4.66% of the variance, and the Substance Use Factor (1-item loading) accounted for 4.21% of the variance.

A visual inspection of the Scree Plot was less informative in suggesting the correct number of factors. The scree plot suggested the data were primarily driven by distress and less by secondary concerns related to treatment, lifestyle, relationship problems, and substance use. Nonetheless, the scree plot confirms that the Cancer Support Source Program significantly captures symptoms and concerns related to distress, which supports the use of the Cancer Support Source as a psychosocial distress screening instrument in a heterogeneous population of patients with cancer.

A recent study applied an exploratory factor analysis (EFA) to the 29-item Cancer Problems in Living Scale (CPILS) with a very large data set of patients with heterogeneous cancer types (Zhao et al., 2009). These researchers identified a 3, 4, and 5 factor solution from their EFA. Their 5 factor solution resulted in the following subscales: 1) physical distress; 2) emotional distress; 3) employment/financial problems; 4) friends and family relations; and 5) fear of recurrence. Four of their five subscales or factors are similar to what was found in this study utilizing an EFA on the Cancer Support Source Questionnaire. The exception being that the researchers found a fear of recurrence factor and our EFA findings found a substance use factor. It is important to note that the CPILS does not contain Action items to direct the clinician to provide specific services.

Subscale Findings by Cancer Location

Patients in this sample were divided into groups by the location of their cancer. Four cancer location groups were sufficiently large to statistically compare to one another. They were

breast, head and neck, lung, and gynecologic cancer. No significant multivariate differences on the MANOVA were found between cancer group locations and the five subscales. However, since the Lifestyle Factor approached significance on the multivariate F test ($p = .06$), ad hoc tests were conducted for this subscale by these four cancer locations. Two significant differences emerged with ad hoc testing. That is, the Breast Cancer group's Lifestyle scores were higher than the Gynecologic Cancer group, and lower than the Lung Cancer group. These findings indicate that further research on the impact of cancer location on lifestyle issues is warranted. We are hopeful that future studies could replicate these findings and in addition, include more complex patient variables such as cancer type, stage of cancer, duration, and type of cancer treatment.

Action Subscale Scores

One of the features of the Cancer Support Source Questionnaire that distinguishes it from other illness impact questionnaires is the companion action items to each specific question of concern. We developed subscales for the Action items to examine whether there was any utility in summarizing parallel Action subscales with the factor scores described above. This was accomplished by simply summing the Action items by subscale. It was found that the resulting Action subscales were highly correlated with their companion Concern subscales and provided little additional information for interpretation. Therefore, it is recommended that the action items be used as they are and not be arranged into subscales. As they stand, the Action items are an effective way to facilitate discussion and intervention with an individual patient.

Depression Subscale and Distress Concern Subscale

The extracted Distress Concern Subscale was found to be highly correlated with the existing 4-item depression subscale. This indicates there is a strong relationship between the Distress Concern Subscale found in this study and the existing depression subscale in the Cancer Support Source Program. These findings illustrate the Distress Concern Subscale may indeed capture symptoms of depression in addition to distress.

Recommendations

The Cancer Support Source Program as it is currently used allows the clinician to drill down to the very specific service needs of the individual patient. In fact, the 25-items represent 25 different potential services the patient may require. From a psychometric perspective this approach is referred to as an ideographic approach. The Concern subscales developed here for the Cancer Support Source Program allows comparison of patient's needs at a construct level of analysis. With this nomothetic approach, the patient's level of distress in these five general areas of need may be evaluated and contrasted using normative values for different populations. That is, patients with extreme scores on one or more of the Concern subscales can be compared to other patients with that type of cancer. As they stand, the single items of concern in the Cancer Support Source Program are useful, but they may fail to capture the complete meaning that a subscale can portray; Distress, Treatment Management and Decisions, Lifestyle, and Relationship factors are complex latent constructs with many facets and implications; a single item may miss the larger issue at hand. That is, single items may miss the forest for the trees. It is thereby recommended that the Concern subscales be used to inform clinicians in a heuristic manner. It is also recommended that the Action items be retained and used as currently indicated.

The Action items give the Cancer Support Source Questionnaire its unique and distinctive ideographic quality. Since the Concern subscales correlates highly with the Action items when they are summed into subscales, nothing is lost, and in fact the utility of the questionnaire is potentially expanded. This enhancement in clinical utility is also demonstrated with the high correlation findings between the Distress Concern Subscale and the existing depression subscale.

The development of the Concern subscales produced by an exploratory factor analysis is easily scored. The item-composition of each of the subscales facilitates and targets parsimonious areas to discuss with the patient in cancer care. This allows for a greater breadth of information of potential areas of need to address with the patient and enhances the patient's ability to ascertain valuable information and/or resources regarding their cancer care.

Future Directions

An area of improvement for the Cancer Support Source Program could be eliminating the 2 or 3 items with lower loadings on the Distress Factor, and the 1 or 2 items with lower loadings on the Treatment Management and Decision Factor. This would shorten the questionnaire without affecting the reliability of those scales. This could also make room for creating and adding new items for the Relationship and Substance Use subscales. Since the Relationship and Substance Use factors could not produce internally consistent subscales with only 1 or 2 items, adding items to those scales will enhance their psychometric potential. Relationship and Substance Use issues are clinically relevant and important constructs for this population. Adding items would enhance the reliability of the Relationship and Substance Use subscales and provide a more robust understanding of these specific areas of need in this clinical population.

The Substance Use subscale presents challenges for the settings that the Cancer Support Questionnaire is often used. While this subscale can identify patients that warrant referral for substance abuse intervention, not all community settings have access to such referrals. Furthermore, the definition of addiction in these settings requires consideration of individual disease factors and mortality considerations. Even in hospital settings, Cancer Survivor and Support services are not generally considered a mental health or addiction treatment service, thus this information gleaned from this subscale may need to be segregated to protected areas of the medical record. Nonetheless, whether in a hospital or community setting, the substance use question is important. Employing the Cancer Support Source Program can suggest additional screening for substance abuse and referral and/or intervention in as minimally intrusive manner as possible (Tai, Wu, & Clark, 2012).

It is recommended the Concern subscale findings from this research study be used to help identify normative clinical cut-offs for the Cancer Support Source Program in future studies. As of now, cut-off scores for the Cancer Support Source Program are arbitrary and are determined individually by each site employing this instrument. The means and standard deviations for the Concern subscales by cancer location group reported in this study may contribute to the development of clinical cut-off recommendations.

Lastly, the preliminary research presented here demonstrated an extracted factor model that was internally consistent and had adequate discriminant and face validity. Therefore, future studies should employ the factors found in this study as a template for further confirmatory procedures (CFA) which will be conducted in the near future with the second sample described above.

Impact of Findings

Assessing distress is a critical aspect of cancer care and many studies have indicated that well-being and quality of life have a significant impact on survival, treatment, and healing outcomes (Anderson, Kiecolt-Glaser, & Glaser, 1994). The findings presented here confirm the heterogeneous impact and prevalence of distress and quality of life factors in the cancer patient population. This study demonstrates how different distress factors are of primary concern in patients with various cancer locations. Finally, it contributes to the available tools for recognizing, screening for, and providing appropriate referral and services for patients with cancer in the areas of distress, treatment management and decisions, lifestyle, relationship, and substance use problems.

**APPENDIX A: ORLANDO HEALTH APPROVAL LETTER CONFIRMING
INSITUTATIONAL REVIEW BOARD EXEMPTION**

1414 Kuhl Ave.
Orlando, FL 32806
321.843.7000

orlandohealth.com

FWA # 00000584

DATE:	November 21, 2016
TO:	Diane Robinson, PhD
FROM:	Orlando Regional Medical Center (ORMC) IRB
PROJECT TITLE:	[982172-1] Analyzing levels of psychosocial distress and need for resources from psychosocial distress screening results: A quality project
REFERENCE #:	16.148.11
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF NOT RESEARCH
DECISION DATE:	November 21, 2016

Thank you for your submission of New Project materials for this project. The Orlando Regional Medical Center (ORMC) IRB has determined this project does not meet the definition of human subject research under the purview of the IRB according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact the IRB Office at (321) 841-5895. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Orlando Regional Medical Center (ORMC) IRB's records.

- 1 -

Generated on IRBNet

APPENDIX B: UCF LETTER CONFIRMING ORLANDO HEALTH INSITUTATIONAL REVIEW BOARD EXEMPTION

Notice that UCF will Rely Upon Other IRB for Review and Approval

From : **UCF Institutional Review Board**
FWA00000351, IRB00001138

To : **Emily J. Ross**

Date : **April 03, 2017**

IRB Number: **SBE-17-13008**

Study Title: **Analyzing levels of psychosocial distress and need for resources from psychosocial distress screening results: A quality project**

Dear Researcher:

The research protocol noted above was reviewed by the University of Central Florida IRB Designated Reviewer on April 03, 2017. The UCF IRB accepts the Orlando Health's Institutional Review Board review and approval of this study for the protection of human subjects in research. **The expiration date will be the date assigned by the Orlando Health's Institutional Review Board and the consent process will be the process approved by that IRB.**

This project may move forward as described in the protocol. It is understood that the Orlando Health's IRB is the IRB of Record for this study, but local issues involving the UCF population should be brought to the attention of the UCF IRB as well for local oversight, if needed.

All data, including signed consent forms if applicable, must be retained and secured per protocol for a minimum of five years (six if HIPAA applies) past the completion of this research. Any links to the identification of participants should be maintained and secured per protocol. Additional requirements may be imposed by your funding agency, your department, or other entities. Access to data is limited to authorized individuals listed as key study personnel.

Failure to provide a continuing review report for renewal of the study to the Orlando Health's IRB could lead to study suspension, a loss of funding and/or publication possibilities, or a report of noncompliance to sponsors or funding agencies. If this study is funded by any branch of the Department of Health and Human Services (DHHS), an Office for Human Research Protections (OHRP) IRB Authorization form must be signed by the signatory officials of both institutions and a copy of the form must be kept on file at the IRB office of both institutions.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Kanielle Chap

Signature applied by Kamille Chaparro on 04/03/2017 01:57:05 PM EDT

IRB Coordinator

APPENDIX C: CANCER SUPPORT SOURCE PROGRAM TEST ITEMS

UFHealth | ORLANDO HEALTH®
CANCER CENTER

Today, how concerned are you about...? *(Please circle one option)*	*Please let us know how we can help you...* *(please check all that apply)*
1. Eating and nutrition 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	☐Have a staff person talk with you. ☐Provide you additional information. ☐No action needed.
2. Feeling irritable 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	☐Have a staff person talk with you. ☐Provide you additional information. ☐No action needed.
3. Moving around (walking, climbing stairs, lifting, etc.) 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	☐Have a staff person talk with you. ☐Provide you additional information. ☐No action needed.
4. Communicating with your doctor 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	☐Have a staff person talk with you. ☐Provide you additional information. ☐No action needed.
5. Sleep Problems 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	☐Have a staff person talk with you. ☐Provide you additional information. ☐No action needed.
6. Changes or disruptions in work, school, or home life 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	☐Have a staff person talk with you. ☐Provide you additional information. ☐No action needed.

7. Feeling sad or depressed 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
8. Transportation to treatment and appointments 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
9. Pain and/or physical discomfort 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
10. Body image and feelings about how you look 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
11. Feeling nervous or afraid 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
12. Worrying about the future and what lies ahead 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
13. Making a treatment decision 1 2 3 4 5 Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.

14. Intimacy, sexual function and/or fertility **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.

15. Feeling lonely or isolated **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
16. Health insurance or money worries **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
17. Problems in your relationship with your spouse/partner **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
18. Feeling too tired to do the things you need or want to do **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
19. Managing side effects of treatment (nausea, swelling, etc.) **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
20. Worrying about family, children and/or friends **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.

21. Recent weight change (gain or loss) **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.

Today, how concerned are you about…?	*Please let us know how we can help you…* *(please check all that apply)*
22. Exercising and being physically active **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
23. Tobacco or substance use – by you or someone in your household **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
24. Finding reliable information about complementary or alternative practices **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.
25. Finding meaning and purpose in life **1** **2** **3** **4** **5** Not at all Slightly Moderately Seriously Very Seriously	□Have a staff person talk with you. □Provide you additional information. □No action needed.

26. What type of cancer do you have?
 	
  ☐ Blood   ☐ Gynecologic   ☐ Pancreatic
  ☐ Brain and Spine   ☐ Head and Neck   ☐ Prostate
  ☐ Breast   ☐ Liver   ☐ Skin
  ☐ Gastrointestinal ☐ Lung ☐ Other	

27. Please let us know if you have any additional comments.

APPENDIX D: DESCRIPTIVE STATISTICS OF ITEMS (N = 317)

Item Number	Mean (*M*)	Standard Deviations (*SD*)
1	3.04	1.36
2	2.17	1.22
3	2.12	1.29
4	2.12	1.41
5	2.31	1.33
6	2.25	1.29
7	2.18	1.23
8	1.61	1.09
9	2.46	1.27
10	2.11	1.21
11	2.28	1.26
12	2.68	1.30
13	2.31	1.34
14	1.59	1.05
15	1.58	.98
16	2.54	1.40
17	1.29	.81
18	2.38	1.23
19	2.49	1.26
20	2.16	1.26
21	1.90	1.18
22	2.39	1.26
23	1.27	.85
24	1.95	1.23
25	1.73	1.20

APPENDIX E: KMO INDEX AND BARTLETT'S TEST OF SPHERICITY

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.93
Bartlett's Test of Sphericity	Approx. Chi-Square	3620.54
	Df.	300
	Sig.	0.00

APPENDIX F: SUBSCALE SCORES BY 12 CANCER LOCATIONS

Cancer Location $M(SD)$	Factor Subscale				
	Distress	Treatment Management and Decisions	Lifestyle	Relationship	Substance Use
Breast	2.21 (.96)	2.28 (.90)	2.18 (.92)	1.52 (.92)	1.25 (.84)
Blood	2.09 (.76)	2.14 (.74)	2.16 (.58)	1.25 (.46)	1.11 (.32)
Lung	2.56 (.97)	2.66 (.96)	2.74 (.87)	1.38 (.69)	1.71 (1.38)
Head and Neck	2.23 (.88)	2.27 (.87)	2.20 (.87)	1.55 (.84)	1.27 (.78)
Gynecologic	2.19 (.95)	2.12 (.76)	2.11 (.91)	1.20 (.40)	1.41 (1.08)
Gastrointestinal	2.16 (.69)	2.33 (.77)	2.09 (.75)	1.47 (.72)	1.23 (.83)
Skin	1.67 (.50)	1.73 (.68)	1.94 (.79)	1.04 (.14)	1.00 (0.00)
Prostate	1.88 (.66)	2.08 (1.00)	2.25 (0.96)	1.58 (0.81)	1.31 (0.85)
Liver	1.56 (0.00)	2.00 (0.00)	2.00 (0.00)	1.00 (0.00)	1.00 (0.00)
Brain and Spine	2.13 (1.06)	2.02 (1.02)	1.90 (1.14)	1.67 (.75)	1.00 (0.00)
Pancreatic	2.78 (0.00)	1.75 (0.00)	3.60 (0.00)	1.00 (0.00)	1.00 (0.00)
Multiple	2.40 (1.00)	2.28 (.82)	2.73 (1.01)	1.61 (1.15)	1.05 (.23)

Note. Standard deviations appear in parentheses below means.

APPENDIX G: INITIAL COMMUNALITIES

Item Number	Extraction
1	.46
2	.54
3	.73
4	.51
5	.43
6	.58
7	.76
8	.52
9	.64
10	.48
11	.75
12	.73
13	.63
14	.67
15	.58
16	.37
17	.67
18	.59
19	.68
20	.54
21	.53
22	.67
23	.50
24	.52
25	.49

REFERENCES

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., . . . Takeda, F.
(1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A
Quality-of-Life Instrument for Use in International Clinical Trials in Oncology. *JNCI
Journal of the National Cancer Institute*, *85*(5), 365-376. doi:10.1093/jnci/85.5.365

Abdi, H. and Williams, L. J. (2010), Principal component analysis. *Wiley Interdisciplinary*
Reviews: *Computational Statistics*, *2*(4), 433-459.

Adler, N. E., & Page, A. E. (2008). *Cancer care for the whole patient: Meeting psychosocial
health needs*. National Academies Press.

Allison, T. G., Williams, D. E., Miller, T. D., Patten, C. A., Bailey, K. R., Squires, R. W., &
Gau, G. T. (1995). Medical and economic costs of psychological distress in patients with
coronary artery disease. *Mayo Clinic Proceedings*, *70*(8), 734-742. doi:10.4065/70.8.734

American College of Surgeons Commission on Cancer. *Cancer Program Standards 2012*,
Version 1.1: Ensuring Patient-Centered Care.
http://www.facs.org/cancer/coc/programstandards2012.html.

Andersen, B. L., Kiecolt-Glaser, J. K., & Glaser, R. (1994). A Biobehavioral Model of Cancer
Stress and Disease Course. *The American Psychologist*, *49*(5), 389–404.

Basu, S., Dasgupta, P. S., & Chowdhury, J. R. (1995). Enhanced tumor growth in brain
dopamine-depleted mice following 1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine
(MPTP) treatment. *Journal of Neuroimmunology*, *60*(1-2), 1-8. doi:10.1016/0165-
5728(95)00044-3

Beavers, A. S., Lounsbury, J. W., Richards, J. K., Huck, S. W., Skolits, G. J., & Esquivel, S. L.

(2013). Practical Considerations for Using Exploratory Factor Analysis in Educational

Research. *Practical Assessment*, *Research & Evaluation*, *18*(6).

Bottomley, A. (2002). The Cancer Patient and Quality of Life. *The Oncologist*, *7*(2), 120-125.

doi:10.1634/theoncologist.7-2-120

Brennan, M. E., Gormally, J. F., Butow, P., Boyle, F. M., & Spillane, A. J. (2014). Survivorship

care plans in cancer: a systematic review of care plan outcomes. *British journal of

cancer*, *111*(10), 1899-1908.

Brown, J. D. (2009). Statistics Corner. Questions and answers about language testing statistics:

Principal components analysis and exploratory factor analysis: Definitions, differences,

and choices. *Shiken: JALT Testing & Evaluation SIG Newsletter*, *13*(1), 26-30. Retrieved

October 30, 2016 from http://jalt.org/test/bro_29.htm

Buzaglo, J.S., Miller, M.F., Gayer, C., Morris, A., & Golant, M. (2013).

*CancerSupportSourceTM: Validating a Web-based Distress Screening Tool in the

Community*. Poster session presented at the 18th Annual National Comprehensive Cancer

Network, Hollywood, FL.

Buzaglo J.S., Miller, M.F., Golant, M., Longacre, M.L., & Kennedy, V. (2016). *Discriminatory

Power of a 15-Item Distress Screening Tool Among Those at Risk for Depression:

Implications for Triage Post Distress Screening.* Poster Session presented at the 21st

Annual National Comprehensive Cancer Network, Hollywood, FL.

Buzaglo, J. S., Miller, M. F., Kennedy, V., Longacre, M. L., & Golant, M. (2016). *Cancer-

related distress among different racial-ethnic groups from a community-based distress

screening program.* Poster session presented at the 37th annual meeting and scientific

sessions of the Society of Behavioral Medicine, Washington, DC.

Buzaglo, J. S., Miller, M. F., Kennedy, V., Longacre, M. L., Golant, M., Amsellem, M., &
Robinson, P.A. (2016). *Cancer-related distress and unmet needs among newly diagnosed
and longer-term cancer survivors from a community-based distress screening program.*
Poster session presented at the ASCO Cancer Survivorship Symposium: Advancing Care
and Research, San Francisco, CA.

Carlson, L. E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., … Bultz, B. D.
(2004). High levels of untreated distress and fatigue in cancer patients. *British Journal of
Cancer*, *90*(12), 2297–2304. http://doi.org/10.1038/sj.bjc.6601887

Centers for Disease Control and Prevention. (2016). *Health-related Quality of Life.* Retrieved
from http://www.cdc.gov/hrqol/concept.htm

Comrey, A.L. (1973). *First course in factor analysis*. New York: Academic Press, Inc.

Costanzo, E. S., Ryff, C. D., & Singer, B. H. (2009). Psychosocial adjustment among cancer
survivors: Findings from a national survey of health and well-being. *Health Psychology*,
28(2), 147-156. doi:10.1037/a0013221

Costello, A.B., & Osborne, J.W. (2005). Best practices in exploratory factor analysis: Four
recommendations for getting the most from your analysis. *Practical Assessment*,
Research & Evaluation, *10*(7), 1-9.

Daudt, H., Mossel, C. V., Dennis, D., Leitz, L., Watson, H., & Tanliao, J. (2014). Survivorship
care plans: A work in progress. *Current Oncology*, *21*(3), 466. doi:10.3747/co.21.1781

Escalante, C. P., Hesketh, P. J., & Savarese, D. M. (2013). Cancer-related fatigue: Prevalence,
screening and clinical assessment.

Everitt, B.S. (1975). Mulitvariate analysis: The need for data, and other problems. *British
Journal of Psychiatry*, *126*(2), 37-40.

Fallowfield, L., Ratcliffe, D., Jenkins, V., & Saul, J. (2001). Psychiatric morbidity and its
    recognition by doctors in patients with cancer. *British Journal of Cancer*, *84*(8), 1011-
    1015. doi:10.1054/bjoc.2001.1724

Faul, L. A., Rivers, B., Shibata, D., Townsend, I., Cabrera, P., Quinn, G. P., & Jacobsen, P. B.
    (2012). Survivorship Care Planning in Colorectal Cancer: Feedback from Survivors &
    Providers. *Journal of Psychosocial Oncology*, *30*(2), 198-216.
    doi:10.1080/07347332.2011.651260

George, D., & Mallery, P. (2003). *SPSS for Windows step by step: A simple guide and reference.*
    11.0 update (4th ed.). Boston MA: Allyn and Bacon.

Gorsuch, R.L. (1983). *Factor analysis*. Hillsdale, NJ: Erlbaum.

Guadagnoli, E., & Velicer, W.F. (1988). Relation of sample size to the stability of component
    patterns. *Psychological Bulletin*, *103*(2), 265-275.

Hair, J., Anderson, R.E., Tatham, R.L., & Black, W.C. (1995). *Multivariate data analysis* (4th
    ed.). New Jersey: Prentice-Hall Inc.

Heydarnejad, M., Hassanpour, D. A., & Solati, D. K. (2011). Factors affecting quality of life in
    cancer patients undergoing chemotherapy. *African Health Sciences*, *11*(2), 266–270.

Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*.
    Washington, DC: The National Academies Press, 2008. doi:10.17226/11993.

Keller, M., Sommerfeldt, S., Fischer, C., Knight, L., Riesbeck, M., Löwe, B., Herfarth, C.,
    & Lehnert, T. (2004). Recognition of distress and psychiatric morbidity in cancer
    patients: A multi-method approach. *European Society for Medical Oncology*, *15*(8),
    1243–1249.

Mayer, D.K., Birken, S.A., Check, D.K., & Chen, R.C. (2015) Summing

it up: An integrative review of studies of cancer survivorship care plans (2006–2013). *American Cancer Society*, *121*(7), 978–996.

Merckaert, I., Libert, Y., Delvaux, N., Marchal, S., Boniver, J., Etienne, A., … Razavi, D. (2005). Factors that influence physicians' detection of distress in patients with cancer. *Cancer*, *104*(2), 411-421. doi:10.1002/cncr.21172

Miller, M. F., Buzaglo, J. S., Clark, K. L., Loscalzo, M. J., Kennedy, V., Taylor, J., … Golant, M. (2012). Demonstrating the psychometric properties of a problem-related distress screener in a community sample of 319 cancer survivors. *Psycho-Oncology*, *22*(6), 1249-1257. doi:10.1002/pon.3124

Miller, M. F., Mullins, C. D., Onukwugha, E., Golant, M., & Buzaglo, J. S. (2014). Discriminatory power of a 25-item distress screening tool: A cross-sectional survey of 251 cancer survivors. *Quality of Life Research*, *23*(10), 2855-2863. doi:10.1007/s11136-014-0742-4

Moreno-Smith, M., Lutgendorf, S. K., & Sood, A. K. (2010). Impact of stress on cancer metastasis. *Future Oncology*, *6*(12), 1863-1881. doi:10.2217/fon.10.142

National Comprehensive Cancer Network. Distress Management Clinical Practice Guidelines in Oncology (Version 1.2014). Retrieved from http://www.nccn.org/professional/physician_gls/pdf/distress.pdf

Pandey, R. A., Dhungana, G. P., Twi, J. T., Byanju, S., & Khawas, B. (2015). Quality of Life of Patients Undergoing Cancer Treatment in BP Koirala Memorial Cancer Hospital, Bharatpur, Chitwan, Nepal. *American Journal of Cancer Prevention*, *3*(2), 35-44.

Pett, M.A., Lackey, N.R., & Sullivan, J.J. (2003). *Making Sense of Factor Analysis: The use of*

factor analysis for instrument development in health care research. California: Sage

Publications Inc.

Pirl, W. F., Muriel, A., Hwang, V., Kornblith, A., Greer, J., Donelan, K., ... Schapira, L. (2007).

Screening for psychosocial distress: A national survey of oncologists. *J Support Oncol*,

5(10), 499-504.

Phillips, M. R. (2009). Is distress a symptom of mental disorders, a marker of impairment, both

or neither? *World Psychiatry*, *8*(2), 91-92.

Rietveld, T. & Van Hout, R. (1993). *Statistical Techniques for the Study of Language and

Language Behaviour*. Berlin – New York: Mouton de Gruyter.

Rodriguez, K. L., Bayliss, N., Alexander, S. C., Jeffreys, A. S., Olsen, M. K., Pollak, K. I., …

Arnold, R. M. (2010). How oncologists and their patients with advanced cancer

communicate about health-related quality of life. *Psycho-Oncology*, *19*(5), 490-499.

doi:10.1002/pon.1579

Sapnas, K.G., & Zeller, R.A. (2002). Minimizing sample size when using exploratory factor

analysis for measurement. *Journal of Nursing Measurement*, *10*(2),135-153.

Shalom, M. M., Hahn, E. E., Casillas, J., & Ganz, P. A. (2011). Do Survivorship Care Plans

Make a Difference? A Primary Care Provider Perspective. *Journal of Oncology Practice*,

7(5), 314-318. doi:10.1200/jop.2010.000208

Smith, M., Lutgendorf, S. K., & Sood, A. K. (2010). Impact of stress on cancer metastasis.

Future Oncology, *6*(12), 1863–1881. doi:10.2217/fon.10.142

Spiegel, D., & Nemeroff, C. B. (1997). Psychosocial aspects of breast cancer treatment.

Seminars in Oncology-Supplements, *24*(1), 36-47.

Sprague, B. L., Dittus, K. L., Pace, C. M., Dulko, D., Pollack, L. A., Hawkins, N. A., & Geller, B. M. (2013). Patient satisfaction with breast and colorectal cancer survivorship care plans. *Clinical Journal of Oncology Nursing*, *17*(3), 266-272. doi:10.1188/13.cjon.17-03ap

Stevens, J. P. (2002). *Applied multivariate statistics for the social sciences* (4th ed.). Hillsdale, NS: Erlbaum.

Swisher, L.L., Beckstead, J.W., & Bebeau, M.J. (2004). Factor analysis as a tool for survey analysis using a professional role orientation inventory as an example. *Physical Therapy, 84*(9), 784-799.

Taylor, S., Harley, C., Campbell, L. J., Bingham, L., Podmore, E. J., Newsham, A. C., … Velikova, G. (2011). Discussion of emotional and social impact of cancer during outpatient oncology consultations. *Psycho-Oncology*, *20*(3), 242-251. doi:10.1002/pon.1730

Tabachnick, B.G., & Fidell, L.S. (2007). *Using Multivariate Statistics*. Boston: Pearson Education.

Tabachnick, B.G., & Fidell, L.S. (2013). *Using Multivariate Statistics* (6th ed.). United States of America: Pearson Education, Inc.

Tai, B., Wu, L.-T., & Clark, H. W. (2012). Electronic health records: Essential tools in integrating substance abuse treatment with primary care. *Substance Abuse and Rehabilitation*, *3*, 1–8. http://doi.org/10.2147/SAR.S22575

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International journal of medical education*, *2*, 53-55.

Thompson. B. (2004). *Exploratory and confirmatory factor analysis: Understanding concepts and applications*. Washington, DC: American Psychological Association.

Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for Emotional Distress in Cancer Patients: A Systematic Review of Assessment Instruments. *JNCI Journal of the National Cancer Institute*, *101*(21), 1464-1488. doi:10.1093/jnci/djp336

Williams, B., Onsman, A., & Brown, T. (2014). Exploratory factor analysis: A five-step guide for novices. *Australasian Journal of Paramedicine, 8*(3). Retrieved from https://ajp.paramedics.org/index.php/ajp/article/view/93/90

Yaremko, R.M., Harari, R.C., Harrison, E., & Lynn, E. (1986). *Handbook of research and quantitative methods in psychology*: *For students and professionals*. Hillsdale: Lawrence Erlbaum Associates.

Yong, A.G. & Pearce, S. (2013). A beginner's guide to factor analysis: Focusing on exploratory factor analysis. *Tutorial in Quantitative Methods for Psychology*, *9*(2), 70-94.

Zabora, J., Brintzenhofeszoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, *10*(1), 19-28.

Zhao, L., Portier, K., Stein, K., Baker, F., & Smith, T. (2009). Exploratory factor analysis of the Cancer Problems in Living Scale: A report from the American Cancer Society's studies of cancer survivors. *Journal of Pain and Symptom Management*, *37*(4), 676-686.