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Regis University
Rueckert-Hartman College for Health Professions
Loretto Heights School of Nursing
Doctor of Nursing Practice Capstone Project

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Screening for Distress in Ambulatory Oncology Patients: The COPE Project

Denise A. Sartz

Submitted as Partial Fulfillment for the Doctorate of Nursing Practice Degree

Regis University

September 18, 2013

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Executive Summary

Screening for Distress in Ambulatory Oncology Patients: The COPE Project

Problem

Approximately 1.6 million new cancer cases are expected to be diagnosed in 2012 (American Cancer Society, ACS, 2012). Recent studies have found that 20-50% of newly diagnosed and recurrent cancer patients demonstrate a significant level of distress (Carlson, Waller & Mitchell, 2012; Mitchell et al., 2011; Swanson & Koch, 2010). Unfortunately less than half of distressed patients with cancer are identified and referred for psychosocial help (Kadan-Lottick, Vanderwerker, Block, Zhang & Prigerson, 2005). Elevated levels of distress in cancer patients has been associated with decreased adherence to treatment, difficulty making treating decisions, extra medical visits, poorer quality of life, and greater stress for the oncology team (Fann, Ell, & Sharp, 2012). The National Comprehensive Cancer Network (NCCN, 2012) recommends that all patients be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated. Based upon this recommendation, the following evidence-based project about the population, intervention, comparison, and outcome (PICO) was developed: Will oncology patients receiving care in a rural ambulatory infusion center who participate in a comprehensive psychosocial assessment program experience a decrease in distress levels?

Purpose

The purpose of this Doctorate of Nursing Practice (DNP) Capstone Project was to identify, assess, and refer patients who are experiencing an elevated level of distress as measured by the NCCN Distress Thermometer.

Goal

The goal of this project was to decrease the psychosocial distress level in patients receiving chemotherapy.

Objective

The primary objective of this evidence-based practice project was to decrease distress in oncology patients. The secondary objective was to formally adopt the NCCN clinical practice guidelines for distress management in ambulatory oncology patients.

Plan

The NCCN Distress Thermometer (DT) was utilized to measure the distress level of ambulatory oncology patients currently receiving chemotherapy in an outpatient infusion center. The capstone project received Institutional Review Board approval from Regis University as well as the New England Institutional Review Board and met exempt status.

Outcomes and Results

A total of 21 ambulatory oncology patients participated in this project. The majority of patients (57%) presented with clinical evidence of moderate to severe distress as evidenced by a distress score of ≥ 4 . Physical problems were the most frequently identified source of distress. Data analysis revealed an overall decrease in distress scores. However, there was not a statistically significant difference in individual distress scores. The NCCN Distress Thermometer facilitated the identification, assessment, and treatment of distress in ambulatory oncology patients. As a result of this project, the NCCN Distress Management clinical practice guidelines have been formally integrated into routine nursing assessments.

Acknowledgements

I would like to thank my husband Greg and daughter Megan for their unconditional love, support, and patience during my doctorate program.

I am continually humbled and inspired by my patient's courage, tenacity, and perseverance. Thank you, Kent, for leaving a legacy. You taught me how to thrive despite the presence of less than perfect conditions.

Table of Contents

| | |
|--|-----|
| I. Preliminary Pages | i |
| A. Copyright Page | i |
| B. Executive Summary | ii |
| C. Acknowledgements | iii |
| D. Table of Contents | iv |
| E. List of Tables | v |
| F. List of Appendices | vi |
| II. Problem Recognition and Definition | 1 |
| A. Problem Statement | 2 |
| B. Theoretical Foundation | 2 |
| C. Literature Review | 4 |
| III. Project Plan and Evaluation | 12 |
| A. Market/Risk Analyses | 12 |
| B. Strengths, Weaknesses, Opportunities, and Threats | 13 |
| C. Needs, Resources, and Sustainability | 14 |
| D. Feasibility/Risks/Unintended Consequences | 14 |
| E. Stakeholders and Project Team | 14 |
| F. Cost-Benefit Analysis | 15 |
| IV. Project Objectives | 16 |
| A. Mission and Vision | 16 |
| B. Outcomes Objectives | 16 |

| | |
|---|----|
| V. Evaluation Plan | 16 |
| A. Logic Model | 16 |
| B. Population and Sampling Parameters..... | 17 |
| C. Methodology and Measurement..... | 17 |
| D. Human Rights Protection | 18 |
| E. Statistics..... | 19 |
| VI. Project Findings and Results | 19 |
| A. Description of the Sample..... | 19 |
| B. Objective One..... | 22 |
| C. Objective Two | 23 |
| D. Limitations, Recommendations, and Implications for Change..... | 24 |
| VII. Summary | 25 |
| VIII. References..... | 26 |
| IX. Appendices | 34 |

List of Tables

| | |
|--|----|
| I. Strengths, Weakness, Opportunities, and Threats (SWOT) Analysis | 15 |
| II. Demographic Characteristics | 23 |

List of Appendices

| | |
|---|-----|
| A. Systematic Review of the Literature | 34 |
| B. Logic Model | 61 |
| C. Project Timeline | 62 |
| D. Participant Letter | 63 |
| E. NCCN Permission Letter | 64 |
| F. NCCN Distress Thermometer Tool | 66 |
| G. NCCN Distress Management Guidelines | 67 |
| H. Chart Audit Data Collection Tool | 131 |
| I. CITI Training Certificate | 134 |
| J. New England IRB Approval Letter | 135 |
| K. Regis University IRB Approval Letter | 136 |
| L. Facility Approval Letter | 137 |
| M. Psychosocial Distress Screening Policy | 138 |
| N. Electronic Health Record Integration | 139 |

Problem Recognition and Definition

Approximately 1,638,910 new cancer cases are expected to be diagnosed in 2012 (American Cancer Society, ACS, 2012). Recent studies have found that 20-50% of newly diagnosed and recurrent cancer patients demonstrate a significant level of distress (Carlson, Waller & Mitchell, 2012; Mitchell et al., 2011; Swanson & Koch, 2010). Unfortunately less than half of distressed patients with cancer are identified and referred for psychosocial help (Kadan-Lottick, Vanderwerker, Block, Zhang & Prigerson, 2005). Elevated levels of distress in cancer patients has been associated with decreased adherence to treatment, difficulty making treating decisions, extra medical visits, poorer quality of life, and greater stress for the oncology team (Fann, Ell, & Sharp, 2012). The National Comprehensive Cancer Network (NCCN, 2012) recommends all patients be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated.

Purpose

The purpose of this Doctorate of Nursing Practice (DNP) Capstone Project was to identify, assess, and refer patients who are experiencing an elevated level of distress as measured by the NCCN Distress Thermometer.

PICO

The Population, Intervention, Comparison, Outcome (PICO) acronym was utilized as the framework to form the practice question and facilitate a systematic review of the literature.

Population: Oncology patients receiving care in a rural ambulatory infusion center

Intervention: Implementation of the NCCN Distress Management guidelines

Comparison: There is no comparison group

Outcome: Decrease in distress scores as measured by the NCCN Distress Thermometer (DT) instrument.

As a result of this Capstone Project, the following PICO question will be answered: Will oncology patients receiving care in a rural ambulatory infusion center who participate in a comprehensive psychosocial assessment program experience a decrease in distress levels?

Project Significance, Scope and Rationale

The role of the doctorate-prepared advanced practice nurse is to bring evidence to patient care (Zaccagnini & White, 2011). According to Zaccagnini & White (2011), “every advanced practice nurse should be a nurse scientist, gathering evidence at the patient’s side, making observations, having experiences, responding to the patient’s experiences, and thinking about reasons, theories, or concepts that might organize the evidence” (p.8). In order to reduce the burden of cancer and treatment-related suffering, the author felt it was imperative to implement an evidence-based, interdisciplinary clinical practice guideline that will address the psychosocial needs of oncology patients. In 2008, the Institute of Medicine (IOM) recommended effective psychosocial care be an integral part of quality cancer care. The committee specifically recommended the use of tools and strategies to improve patient-provider communication; facilitate the identification and assessment of psychosocial health problems, and to design illness and wellness management strategies (IOM, 2008).

Theoretical Foundation

Kolcaba (2010) provided a unique description of comfort in health care. She described comfort as “the immediate state of being strengthened by having the needs for relief, ease, and transcendence addressed in the four contexts of holistic human experience: physical, psychospiritual, sociocultural, and environmental” (Introduction section, para.1). Kolcaba’s

comfort theory can be utilized to determine the existence and extent of unmet needs, designing interventions, and creating measurements of holistic comfort for documentation in practice and research (Kolcaba, as cited in Parker & Smith, 2010). This is particularly relevant to the DNP practice issue because the NCCN distress thermometer addresses the same domains: physical symptoms, spirituality, practical issues, family problems, and spiritual/religious concerns.

Although the concept of comfort is not unique to nursing, Kolcaba has developed a middle-range nursing theory that encourages nurses to define their unique contribution to patient care outside of the biomedical model. According to Kolcaba (2001), nurses are the ones primarily responsible for identifying and assessing the comfort needs of patients who experience a stressful life event. The comfort theory states the process of comforting a patient entails the intention to comfort, to be present, and to deliver comforting interventions based on the patients' and loved ones' unmet needs (Kolcaba, as cited in Parker and Smith, 2010).

The major concepts identified in Kolcaba's comfort theory (2001) are: the identification of health care needs, comfort interventions, intervening variables, health-seeking behaviors, and institutional integrity. Kolcaba (1991) originally described three technical senses of comfort: state, relief, and renewal. These were later described as relief, ease, and transcendence (Kolcaba, 2001). All of these concepts are related to the outcome of comfort and can be measured in terms of both patient comfort and family comfort.

Health care needs are defined as the need for comfort that cannot be met by the patients' traditional support system (Kolcaba, as cited in Parker & Smith, 2010). These needs encompass physical, spiritual, sociocultural and environmental needs that are identified by patients and nurses. In the context of the DNP practice issue, health care needs may include practical

problems (e.g., child care, housing), family problems, emotional problems, spiritual/religious concerns, and physical problems such as appearance, fatigue, nausea, and pain.

Literature Review

The goal of evidence-based practice is to promote optimal healthcare outcomes which are based on critically reviewed clinical evidence as well as the preferences and values of patients and families (Chism, 2013; Eaton & Tipton, 2009). Implementing evidence-based practice (EBP) at the bedside remains a formidable challenge for the majority of nurses. Successful implementation requires a multi-step process including: identifying the problem, formulating a question, finding the evidence, critically appraising and synthesizing the evidence; translating the evidence into practice; and evaluating the EBP change (Houser & Oman, 2011). Evidence-based oncology nursing practice is largely driven through the advancement of innovative scientific research on cancer treatment, supportive care, and promising patient outcomes. An overwhelming amount of data is available to help nurses manage cancer symptoms and side effects. The author has completed a systematic review of the literature in order to identify, select, assess, and summarize similar studies (see Appendix A). Several databases were searched including: CINAHL, MEDLINE, PsycINFO, and the Cochrane Library.

Psychosocial distress was the first key term searched within CINAHL and resulted in 7,093 articles. The search was narrowed by adding the term ‘cancer’ and this resulted in 1,815 articles. Finally, ‘distress thermometer’ was added to psychosocial distress and cancer resulting in 54 articles. A duplicate search was completed in MEDLINE and resulted in an initial 4,171 articles which were narrowed to 1,261 and finally 52 articles. The PsycINFO database revealed an initial 5,280 articles which was narrowed to 982 articles and finally 35 articles. The Cochrane

Library search revealed an initial 26 articles and was narrowed to 11 articles. After the term ‘distress thermometer’ was added to the search list, only one article was identified.

The National Comprehensive Cancer Network (NCCN) defines distress as a “multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and or/spiritual nature that may interfere with the ability to cope effectively with cancer, the physical symptoms, and its treatment” (NCCN, 2012, p. DIS-2). The term “distress” was chosen because it was felt to be less stigmatizing than “psychiatric”, “psychosocial” or “emotional” (NCCN, 2012). Distress symptoms can vary greatly from common feelings of vulnerability, sadness, and fear to problems including severe depression and anxiety that are disabling and require professional intervention (Fitch, 2011). Patient risk factors for distress include: a diagnosis of lung, brain, or pancreatic cancer, disability, and ongoing unmet needs (Carlson, Waller, & Mitchell, 2012; Keir, Calhoun-Eagan, Swartz, Saleh, & Friedman, 2008; Steinberg et al., 2009). Hurria et al. (2009) also found that poor physical function and age (≥ 65) were predictors for elevated distress. Oncology patients residing in a rural area may also have an increased risk for distress (Smith, Limesand, & Alikhan, 2011). Screening for distress as an integral part of psychosocial care has become a major priority for numerous professional organizations as well as cancer treatment centers (Jacobsen & Wagner, 2012).

Due to the potential negative impact on patient outcomes, all patients with cancer should be screened for evidence of psychological distress as part of routine care (Holland & Alici, 2010; Jacobsen, Holland, & Steensma, 2012). However, it has been noted that the process of identifying those needs and rendering the appropriate intervention and/or referral requires an assessment tool that can quickly yet effectively identify patients who are experiencing elevated

levels of distress (Carlson et al., 2012). In an effort to meet this need, Roth et al. (1998) developed a “distress thermometer” that could be administered and interpreted rapidly by clinical staff. Patients who complete this assessment are asked to rate their distress using a scale with scores ranging from 0 (no distress) to 10 (extreme distress). This screening tool also has a problem checklist that highlights five potential areas of difficulty that may be linked to distress: practical, family, emotional, spiritual, and physical. Patients with a score of less than four are considered to have “mild” distress and can be managed by the primary oncology team. Patients with a score of four or greater are considered to have moderate to severe distress and should be referred to the appropriate professional (social worker, chaplain, psychologist, or other specialist) (NCCN, 2012). The National Comprehensive Cancer Network (2012) provides a structured algorithm that guides the clinician in making the appropriate referral based upon the patients’ level of distress. The goal of this assessment tool is not to identify all potential psychiatric disorders but rather to target and offer appropriate referrals for the most common sources of distress such as insurance/financial issues, fatigue, pain, nausea, and spouse/child problems (Holland & Alici, 2010).

Mitchell (2010) completed a review and diagnostic validity meta-analysis for cancer-related distress screening tools. A total of 45 potentially useful short and ultra-short tools tested and utilized within cancer and palliative care settings were identified. Only three of these tools had been tested against robustly defined distress (i.e., distress defined by semi-structured interview) in multiple samples (Mitchell, 2010). Only the Distress Thermometer (DT) and a single verbal question (1Q) were specifically validated against interview-defined distress in more than one independent sample. The DT was found to have a sensitivity of 78.5% and a specificity of 67.4% in multiple independent samples (Mitchell, 2010). Vodermaier, Linden, & Siu (2009)

also completed a systematic review of tools used to screen patients for emotional distress. The authors concluded the DT had a moderate level of reliability (Cronbach's $\alpha \geq 0.60$ and ≤ 0.80) and a moderate level of validity (average sensitivity and specificity ≤ 0.6 and ≤ 0.8). The Distress Thermometer Tool has been identified as an ultra-short, valid, and reliable screening tool that is inexpensive and easy to adopt in a clinical setting (Fulcher & Grosselin-Acomb, 2012; Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Jacobsen et al., 2005; Kendall, Glaze, Oakland, Hansen, & Parry, 2011; Lowery & Holland, 2011; Shimizu et al., 2010; Snowden et al., 2011; Vitek, Rosenzweig, & Stollings, 2007).

Despite the availability of valid and reliable oncology-specific screening tools, screening for distress has not been widely adopted in clinical practice. Jacobsen & Ransom (2007) reported only 53% of NCCN member institutions screen routinely for distress. A physician survey completed by the American Society of Clinical Oncology (ASCO) reported 65% of oncologists screen for distress; however, only 14% of these physicians reported utilizing a standardized screening instrument. Furthermore, only 35% of respondents indicated they were familiar with screening guidelines (Pirl, 2004). Mitchell, Lord, Slattery, Grainger, and Symonds (2012) reported only a minority of clinicians ask their oncology patients about emotional problems. Many clinicians preferred to rely on patients mentioning the problem during an office visit. The authors also reported that only 15% of clinicians use a screening tool and most of the clinicians preferred using their own clinical judgment (Mitchell et al., 2012).

Unfortunately limited data exists on the benefits of screening for emotional distress within the oncology population. Carlson, Groff, Maciejewski, and Bultz (2010) implemented an online distress screening program for new patients with breast and lung cancer. The primary objective of the study was to compare the efficacy of screening on subsequent distress.

Secondary objectives included measures of anxiety and depression and to assess the impact of receiving referrals. Patients were randomly assigned to one of three groups: minimal screening, full screening, and full screening plus triage with a referral to resources. Patients randomized to the minimal screening group had the DT administered but no feedback was given to the patient. Patients in the full screening arm completed the DT, the DT problem checklist, fatigue and pain thermometers, and a test to measure anxiety and depression. Patients were printed a personalized feedback report and a summary report was placed in the electronic medical record. Patients randomized to the triage arm received all of the full screening plus they received a referral to speak to a member of the psychosocial team. The mean baseline score for all participants was high (4.33). Approximately 55% of all patients had a score of ≥ 4 at the time of study enrollment. Patients randomized to the triage group showed significantly lower distress at three months compared with the minimal screening group ($p=0.031$). Patients over the distress cutoff score was significantly lower in the triage group (36%) compared to the full screening (46%) and minimal screening group (48.7%) (Carlson et al., 2010). The authors concluded intensive screening including feedback to patients and care providers followed by an appropriate referral helped to reduce future distress levels (Carlson et al., 2010).

Frost, Zevon, Gruber and Scrivani (2011) utilized the NCCN DT tool to measure the level of distress in head and neck cancer patients receiving chemotherapy in an ambulatory care clinic. A total of 763 patients participated in the pilot study. Approximately 19% of all patients had a score of four or higher on the 10-point DT scale; indicating a moderate to severe level of distress. The most frequently reported physical symptoms were fatigue (29%), pain (21%), sleep (20%), and eating difficulties (13%). Emotional problems included worry (24%), nervousness (19%), and both depression and fearfulness (11%). The authors concluded that early use of the

DT helped to identify post-hospital placement, individual or family counseling needs, and financial issues. Furthermore, this pilot study demonstrated that the DT placed minimal burden on the nursing staff and was easy to implement in an outpatient clinic setting.

Psychological distress among women with newly diagnosed breast cancer has also been studied. Mertz et al. (2012) utilized the DT to determine the characteristics and extent of psychological distress among women at the time of their breast cancer diagnosis. A total of 343 women completed the distress thermometer. When a score of three on the DT was used as the cut-off, 77% of women were categorized as experiencing distress. The results displayed a significant inverse association between distress and age; higher age was associated with lower distress with an odds ratio (OR) per year of 0.96, 95% CI [0.93, 0.98]. Worry (77%) and nervousness (71%) were the most frequently reported problem areas, followed by sleep disturbances (50%), fatigue (49%), and sadness (45%). The authors did not find a significant association between distress levels and the presence of a partner or family support.

Fulcher and Gosselin-Acomb (2007) completed a feasibility pilot study utilizing the distress thermometer in a radiation oncology center. A total of 57 patients completed the distress thermometer during a three month pilot study. The mean baseline distress thermometer score was 2.2. Eight patients had an increase in their distress score over the course of their treatment and 11 patients had a decrease in their score. All other patients had no change in their distress scores over time. The authors did note social worker, chaplain, and mental health referrals increased during this period. Furthermore, the authors noted that patient satisfaction scores were higher post-implementation (88.1% vs. 92.6%). Due to the sample size this particular study did not reach statistical significance. However, it can be argued that clinical significance was reached for several of these patients as well as the institution as a whole.

O'Sullivan, Bowles, Jeon, Ercolano, and McCorkle (2011) studied the impact of advanced practice nursing (APN) interventions on the level of psychological distress during ovarian cancer treatment. The authors hypothesized women with suspected ovarian cancer who received a specialized nursing intervention program would have greater improvement in quality of life measures over time compared to women in an attention-control group. The use of the distress thermometer found that 24 of 32 women reported high levels of distress. Participants were divided into three subgroups: High distress/oncology APN plus referral to psychiatric APN, High distress/oncology APN only/refused psychiatric APN, and low distress/oncology APN only. There was no statistical difference in the mean number of total problems per contact in each of the groups. However, the findings did indicate that women with high levels of distress who received care from both an oncology APN and a psychiatric APN required fewer interventions per contact.

Hammonds (2012), a DNP student at the University of South Alabama, utilized the DT tool to identify elevated levels of distress in breast cancer patients receiving treatment at a university breast cancer clinic. A total of 104 patients participated in this quality improvement project. Patients with a DT score of ≥ 4 were referred to a psychiatric mental health practitioner, social worker, chaplain, dietician, primary care provider, or oncologist. During the project 55% of participants were identified as experiencing a moderate or severe level of distress. The author concluded the DT is a brief and effective tool for identifying distress in oncology patients.

Swanson and Koch (2010) completed a retrospective chart review to collect information about whether or not the utilization of an oncology nurse navigator (ONN) would result in a decreased distress score for adult inpatients. The authors found that patients seen by the ONN tended to have lower distress scores on dismissal but this was not statistically significant.

($p=0.1046$). However, there was a statistically significant effect on patients 65 years of age or younger ($p=0.044$) as well as patients from rural settings ($p=.045$). Skrutkowski et al. (2008) also examined the impact of an oncology nurse navigator on patient distress levels. Patients with lung or breast cancer were assigned to an intervention group with care by a 'pivot nurse' in oncology and usual care by clinic nurses or to a control group with usual care only. Participants in both groups were assessed for symptom distress, fatigue, quality of life, and healthcare resource usage. No significant difference was found in distress levels between the groups over time ($p=0.675$). However, the results did demonstrate a statistical significance in distress over time based upon the type of cancer. Patients with lung cancer had more distress than patients with breast cancer ($p=.023$).

In addition to the data regarding the benefits of distress screening, several authors have addressed the challenges of implementing a distress screening program in clinical practice. Barriers include lack of coordinated evidence-based psychosocial services, financial reimbursement, clinician training/expertise, screening time, resistance to change, and insufficient resources (Absolom et al., 2011; Carlson et al., 2012; Dudgeon et al., 2012; Fann et al., 2012; Fitch, 2011; Jacobsen, 2007; Jacobsen & Ransom, 2007; Madden, 2006; Mitchell, Vahabzadeh, & Magruder, 2011; Pincus & Patel, 2009).

Oncology nurses can play a pivotal role in removing some of these barriers. Nurses must have the knowledge and skills to rapidly and accurately assess the psychosocial needs of their patients. Unfortunately many nurses have not received any formal education or training on how to perform a comprehensive holistic patient assessment. Spade and Mulhall (2010) developed a high-fidelity simulation exercise to teach undergraduate nursing students about the importance of holistic nursing assessments. The Psychosocial Vital Signs (PVS) curriculum was developed to

help nursing students learn how to gather cognitive, affective, spiritual, and behavioral data about their patients (Spade & Mulhall, 2010). The simulation exercise allowed nursing students the opportunity to identify and assess a patient's level of anxiety, coping, and sense of support. Nursing students were also taught how to devise, implement, and evaluate a patient-specific treatment plan. Although this model has not been tested or validated in a clinical setting, it does provide a conceptual framework for an innovative nursing curriculum designed to foster critical thinking and improved communication skills for nursing students.

Pasacreta, Kenefick, and McCorkle (2008) described the "ICAN: Distress Management for Oncology Nursing" online continuing education program designed to help oncology nurses integrate distress screening into their routine patient assessments. Developed by the American Psychosocial Oncology Society (APOS) and the Individual Cancer Assistance Network (ICAN), this webcast is available to any nurse interested in understanding how to identify, assess, and treat psychosocial distress in oncology patients. Content areas include: barriers to psychosocial care, appropriate use of resources, goals and benefits associated with psychosocial intervention, and psychosocial symptom management. This type of training program can help oncology nurses learn more about the essential components of psychosocial oncology and alleviate some of the traditional barriers to implementing a comprehensive distress management program.

Project Plan and Evaluation

Market/Risk Analyses

A comprehensive needs assessment was completed prior to project implementation. This project was endorsed by the local Cancer Committee and is considered to be an integral part of oncology care as defined by the National Comprehensive Cancer Network (NCCN) as well as the American College of Surgeons (ACOS).

While more than 577,190 Americans are expected to die of cancer in 2012, the survival rate for many cancers continues to improve (ACS, 2012). The five-year survival rate for all cancers diagnosed between 2001 and 2007 is 67%, a significant increase from 49% between 1975 and 1977 (ACS, 2012). Unfortunately many advanced cancers are not curable and these patients will require extended periods of multi-modality treatment including numerous chemotherapy regimens with or without radiation therapy. For many patients, cancer will become a chronic disease which will require intensive surveillance and intermittent periods of treatment. As a result, some patients will endure prolonged periods of physical, spiritual, and emotional distress. These problems can adversely affect the quality of patients' lives during their initial chemotherapy as well as many years into survivorship. Unfortunately, these problems can be magnified if a patient has any pre-existing psychological or social stressors that were present prior to the cancer diagnosis (IOM, 2008).

Strengths/Weaknesses/Opportunities/Threats

A comprehensive strengths, weaknesses, opportunities, and threats (SWOT) analysis for the DNP Capstone Project was completed (see Table 1). The project utilized an ultra-short, validated distress assessment tool as well as a comprehensive treatment algorithm. This allowed the advanced practice nurses (APN) the ability to rapidly identify a patient's psychosocial needs, develop an individualized plan of care, and make the appropriate referral for treatment. The factors which might have impacted successful completion of the Capstone Project included the following constraints: clinician training/expertise, competing priorities, attrition rate, and space for privacy. Strategies to increase the likelihood of completion of the Capstone Project included comprehensive staff education, scheduled appointments, collaboration with an interdisciplinary team, and utilization of DNP Capstone mentors.

Needs/Resources/Sustainability

The needs for the project included access to the patient population and their medical record, cooperation from staff and physicians, and institutional review board approval.

Resources included the NCCN Distress Management clinical practice guidelines, statistical analysis software, and interdisciplinary staff. Sustainability of this project is possible because the distress thermometer tool has already been incorporated into the electronic health record (EHR). Furthermore, the hospital cancer committee unanimously approved integrating this comprehensive psychosocial assessment program into the existing oncology service line program.

Feasibility/Risks/Unintended Consequences

Potential risks to this project include lack of acceptance and involvement by key stakeholders, competing priorities, and a reluctance to accept new clinical practice guidelines for distress management. This project may also reveal that patients are unsatisfied with their overall oncology care.

Stakeholders

Stakeholders for this project included: patients, physicians, nurses, insurers, ancillary staff, administrators, researchers, the American College of Surgeons (ACOS), the Joint Commission (JC), the Center for Medicare and Medicaid Services (CMS), and community agencies. The project team included Advanced Practice Registered Nurses (APRNs), infusion nurses, physicians, social workers, chaplains, financial counselors, patient navigator, administrators, and dietitians. Furthermore, additional support was provided by the DNP Capstone Mentor and Regis University DNP Faculty and Capstone Chair.

Table 1

SWOT Analysis

| | |
|--|---|
| <u>Strengths:</u> | |
| Endorsed by Cancer Committee | Proactive, holistic assessment |
| Respected, peer reviewed guidelines | Ultra-short, validated tool |
| Comprehensive treatment algorithm | Interdisciplinary collaboration |
| | American College of Surgeons (ACOS) Accreditation |
| <u>Weaknesses:</u> | |
| Lack of formal referral process | <u>Strategies to overcome:</u> |
| Poorly coordinated psychosocial services | Staff education |
| Clinician training/expertise | Develop a referral algorithm |
| Paper-based assessment | Scan into EMR |
| Unfamiliarity of guidelines | |
| <u>Opportunities:</u> | |
| Decreased distress level | Decreased hospitalizations |
| Improved provider communication | Increased quality of life |
| Improved patient satisfaction | Impetus for new programs |
| Improved patient trust and rapport | Adoption of electronic tools |
| <u>Threats:</u> | |
| Competing priorities | <u>Strategies to overcome:</u> |
| Time constraints | Integrate into chemotherapy education appointment |
| Space for privacy | Utilize assistance of DNP Capstone Mentor |
| Attrition rate | Use of participant letter |
| Reimbursement | Scheduled appointments |

Cost-Benefit Analysis

The costs and benefits of this project were determined prior to implementation. Direct costs included labor and supplies. The average assessment time per patient was 30 minutes. At an average cost of \$55.00/hour x 84 assessments (21 participants x 4 assessments), the APRN salary expense was approximately \$2,310.00. Copier paper and supplies were approximately \$50.00. The Statistical Software Package for Social Sciences (SPSS) was \$55.00. Indirect costs of this project were minimal due to the use of existing space, internet access, and support staff. The benefits of this DNP Capstone Project include: improved patient outcomes, enhanced communication between providers and patients, improved patient satisfaction, improved staff

retention, and enhanced institutional integrity. Furthermore, this project may identify current gaps in oncology care that can be filled by new programs and/or services.

Mission/Vision/Objectives

The mission was to nurture and improve the quality of life for people with cancer. The goal of this project was the successful integration and application of the NCCN Distress Management guidelines for oncology patients. The core values of the Capstone Project included: comfort, compassion, respect, and collaboration. This DNP Capstone Project had a primary and secondary objective. The primary objective was to decrease the distress level in oncology patients receiving care in a rural ambulatory infusion center. The secondary objective was the formal institutional adoption of the NCCN clinical practice guidelines into routine cancer care.

Evaluation Plan

The logic model (see Appendix B) addresses several advanced practice nursing outcome measures including: care-related (cost of care, length of stay, readmission rates, office visits, quality of life); patient-related (compliance, symptom resolution, functional status); and performance-related (job satisfaction, performance ratings, collaboration, and quality of care). According to Kleinpell (2009), these groupings can be used to examine outcomes studies of APN care and help identify future research opportunities. The benchmark target is the incorporation of a standardized tool to identify, assess, and refer patients experiencing a heightened level of distress according to national practice guidelines. Patients appropriately screened and referred for distress will experience a decrease in their overall emotional distress level.

In addition to the numerous potential patient benefits, this project fostered an environment that supports interdisciplinary collaboration. The Institute of Medicine (2001) emphasized the need for providers and institutions to actively collaborate and participate in care

coordination in order to improve patient safety and patient health outcomes. The doctorate-prepared advanced practice nurse should play a pivotal role in establishing these interprofessional teams (American Association of Colleges of Nursing, AACN, 2006). This Capstone Project was the impetus to fostering a professional, collegial relationship with multiple providers and stakeholders at Cheyenne Regional Medical Center.

Study Methodology/Instrumentation/Measurement

This evidence-based practice project consisted of implementing the National Comprehensive Cancer Network (NCCN) guidelines for distress management in oncology patients. All of the participants had a cancer diagnosis and were expected to receive chemotherapy for at least three months. Additional inclusion criteria included the ability to speak, read, and understand English and a baseline Eastern Cooperative Oncology Group (ECOG) score of ≤ 2 . There were 21 participants in the study. The project started on February 19, 2013 and was completed May 17, 2013 (see Appendix C).

At their initial infusion center appointment patients were provided information on the Comprehensive Oncology Patient Evaluation (COPE) project by the primary investigator or assistant investigator for this project. All new patients were asked to participate. Furthermore, all patients who had started chemotherapy within 30 days after Institutional Review Board (IRB) approval were also asked to participate. New chemotherapy patients were provided information about this project during their chemotherapy education session with an advanced practice registered nurse (APRN). Patients were provided a participant letter at the time of their education session (see Appendix D). Patients who already started their treatment (within 30 days after the project had been approved) were asked to participate during one of their subsequent infusions. All patients received extensive information about this project in a private, confidential

office. Time was allotted for patients to ask questions and for the investigator to address any concerns.

The patients were interviewed by either the primary investigator or assistant investigator using the Ambulatory Infusion Center's intake history and assessment forms. Both investigators for this project were advanced practice registered nurses (APRNs) employed at the Ambulatory Infusion Center. Patients were asked to complete the National Comprehensive Cancer Network (NCCN) Distress Thermometer checklist. The Distress Thermometer (DT) is a paper and pencil assessment took approximately five minutes to complete. Permission to utilize the DT had been granted by the National Comprehensive Cancer Network (NCCN) (see Appendix E). The Distress Thermometer instrument asked patients to rate their level of distress within the past week on a scale of 0-10 (0=no distress; 10=extreme distress) and complete the problem check list in each of the five areas linked to distress including practical, family, emotional, spiritual, and physical (see Appendix F). The National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) has a Cronbach's alpha score of 0.86 (Moretz, 2002). A baseline DT assessment was completed by patients at the time they began their chemotherapy infusion or within 30 days of starting their initial infusion, and at least monthly during their chemotherapy infusion visits. Patients with a distress score of ≥ 4 were individually assessed by an advanced practice registered nurse (APRN) and the appropriate referral was made based upon the guidelines in the NCCN treatment algorithm (see Appendix G).

Protection of Human Rights

To protect against the breach of confidential information, the project primary investigator assigned each chart a code number different from their medical record number. This code, not the patients name, appeared on the chart audit data collection instrument form (see Appendix H)

that contains data collected from the patient's chart. The patient names, along with their codes, were stored in a locked file cabinet in the investigator's office. The secondary investigator was a registered nurse with Collaborative Institutional Training Initiative (CITI) certification, was trained on the data collection processes for this project, and was supervised by the primary investigator (see Appendix I). The New England Institutional Review Board as well as the Regis University Institutional Review Board approved this project (see Appendix J and K, respectively). Furthermore, this DNP Capstone Project was approved by the hospital Chief Compliance Officer (see Appendix L). Information was kept on a computer that is password restricted. The demographic information was filed separately from the questionnaires and will be destroyed five years after the close of the study.

Statistics

Data obtained from the chart audit was analyzed using the Statistical Product and Service Solutions (SPSS) software package. The patient's distress scores were analyzed to determine if there had been a decrease in their distress level. Descriptive statistics including frequencies, means, standard deviations, and ranges were completed on demographic data, ECOG scores, and distress scores. A repeated measures ANOVA was utilized to measure changes in distress scores over time. Reliability testing on the NCCN DT instrument was also completed.

Project Findings and Results

Description of the Sample

A total of 21 ambulatory oncology patients participated in this project. See Table 2 for demographic characteristics. The mean age was 63 (range 44 to 84 years). Patients with all stages of cancer were included: stage I (5%), stage II (10%), stage III (29%), and stage IV (48%). The primary goal of treatment was palliation (71%). The most common diagnoses were:

lymphoma (23%), breast cancer (14%), pancreatic cancer (14%), lung cancer (10%), and colorectal cancer (10%). The majority of participants (71%) had an ECOG score of one.

The majority of patients (57%) presented with clinical evidence of moderate to severe distress as evidenced by a distress score ≥ 4 . The mean baseline score was 3.95 (SD, 3) and the median score was four with a range of scores from zero to nine. Physical problems were the most frequently identified source of distress during the initial assessment (19%). Participants were primarily referred to the oncology nurse practitioner for symptom management (95%).

At the time of the second assessment, 29% of patients reported a moderate to severe level of distress. The mean score for the second assessment was 2.52 (SD, 2). The median score was two with a range of scores from zero to seven. Practical problems were the most frequently identified source of distress during the second assessment (14%). Participants were referred to the nurse practitioner (17%) or financial counselor (10%).

Only 16 participants completed a third assessment. Of the patients who completed the third assessment, 38% of them had a distress score of ≥ 4 . Their mean score was 2.5 (SD, 3). The median score was one with a range of scores from zero to nine. The majority of participants reported physical problems (10%). Participants were again primarily referred to the nurse practitioner for symptom management (20%).

The final assessment was completed by six participants. The other participants had completed treatment, died, or had a delay in their treatment beyond the three month timeframe allowed for this project. The mean score for the final assessment was 1.17 (SD, 2). Only one participant had an elevated distress score of ≥ 4 . Demographic data for the six participants who completed all four of the assessments were similar to the total population. The mean age was 67

years (range 56-84). The goal of treatment was palliation (66%) and the most frequent diagnosis was pancreatic cancer (40%). All of these participants had an ECOG score of 0-1.

Table 2
Demographic Characteristics

| Characteristic | Patients | |
|--------------------------|----------|----|
| | No. | % |
| Gender | | |
| Male | 10 | 48 |
| Female | 11 | 52 |
| Ethnicity | | |
| Caucasian | 20 | 95 |
| African American | 1 | 5 |
| Marital Status | | |
| Married | 12 | 57 |
| Single | 1 | 5 |
| Widowed | 3 | 14 |
| Divorced | 5 | 24 |
| Employment Status | | |
| Retired | 12 | 57 |
| Full Time | 4 | 19 |
| Unemployed | 5 | 24 |
| Insurance | | |
| Medicare | 10 | 47 |
| Medicaid | 1 | 5 |
| Private | 8 | 38 |
| Uninsured | 2 | 10 |
| Living Situation | | |
| Alone | 4 | 19 |
| Spouse | 12 | 57 |
| Extended Family | 2 | 10 |
| Other | 3 | 14 |
| Religion | | |
| Catholic | 2 | 10 |
| Presbyterian | 1 | 5 |
| Lutheran | 1 | 5 |
| Christian | 3 | 14 |
| None | 7 | 33 |
| Other | 7 | 33 |
| Comorbidities | | |
| Yes | 17 | 80 |
| No | 4 | 20 |
| Treatment Goal | | |
| Palliative | 15 | 71 |
| Curative | 6 | 29 |

Objective One

A repeated measures ANOVA was completed to determine if there were significant differences in distress scores over time for the six participants. The Mauchly's test of sphericity indicated the assumption of sphericity had not been violated (Chi-square=5.980, $p=0.323$). There was a significant difference noted in distress scores over time ($F=8.149$, $p=0.003$). However, there was not a significant difference found in distress scores with a pairwise comparison ($p=0.323$). This can be explained in part due to the small sample size which impacts the Mauchly's Test of Sphericity.

The Distress Thermometer (DT) was easy to administer and score. Reliability testing was completed on the Distress Thermometer (DT) with a Cronbach's alpha of 0.677. This is slightly lower than the previously reported internal consistency of 0.86 (Mortez, 2002).

Patients who experienced a moderate to severe level of distress (DT score ≥ 4) were referred to the appropriate clinician based upon the NCCN distress management treatment algorithm. The majority of patients experienced elevated levels of distress due to physical problems as a result of their underlying cancer diagnosis or treatment. Physical problems were assessed and treated by the primary oncology team (advanced practice registered nurses and oncologists). Data analysis revealed that interdisciplinary referrals (mental health, social work, and chaplaincy) were limited during this project.

The high prevalence of psychosocial distress seen in this patient population is consistent with what has been reported in the literature. The Distress Thermometer (DT) facilitated the timely identification of concerns, thereby enhancing the opportunity for an early intervention. A high percentage of patients reported an elevated level of distress due to physical concerns at the

time of their initial psychosocial evaluation. Aggressive symptom management and patient education, provided by the APRNs, was paramount to decreasing subsequent levels of distress.

Kolcaba's comfort theory provided an excellent conceptual framework for this evidence-based project. The APRN benefited from developing meaningful relationships, addressing unmet psychosocial, physical, spiritual and environmental needs, and practicing according to her own values and patient care philosophy. Participants had their comfort needs met by engaged, professional, and empathetic nurses who were committed to reducing the level of distress in their patient population. Finally, the healthcare institution may reap the cultural and financial rewards for producing the best possible patient and family outcomes.

Objective Two

The findings of this evidence-based practice project were shared with the interdisciplinary cancer committee. Members of the interdisciplinary cancer committee reaffirmed their commitment to meeting the physical, emotional, spiritual, and practical needs of all cancer patients. The committee unanimously agreed to provide full administrative and clinical support to formally incorporate the NCCN distress management guidelines into routine oncology care. As a result of this project, a policy for psychosocial distress screening was written and approved by the cancer committee (see Appendix M). Furthermore, psychosocial distress screening has been fully integrated into routine oncology care for ambulatory infusion patients.

All oncology patients receiving care in the ambulatory infusion center are now screened for psychosocial distress at their initial visit and at least monthly during treatment. Assessments have been entirely integrated into the electronic health record (see Appendix N). Patients with a distress score of ≥ 4 are evaluated by the oncology advanced practice registered nurse (APRN)

and referred to the appropriate clinician for treatment based upon the NCCN treatment algorithm. Oncology patients with clinical evidence of mild distress (score < 4) are managed by the primary oncology team.

Limitations, Recommendations, Implications for Change

Limitations

The first limitation of this study was the sample size. It was estimated that 70 participants would enroll in this project. However, due to the limited timeframe to complete this project, only 21 patients enrolled. The small sample size may have contributed to the lack of statistical difference seen in individual distress scores over time. Furthermore, this project was conducted in a single institution and there was limited diversity seen within this patient population. Therefore, the results are not generalizable to other practice settings.

Recommendations

Based upon these findings, all patients with cancer should be screened for distress at their initial visit and as clinically indicated. Patients with an elevated level of psychosocial distress should receive a comprehensive treatment plan to address their needs and be referred to the appropriate clinician for evidence-based treatment.

Implications for Change

Advanced practice registered nurses (APRNs) are in a unique position to make a difference in screening and managing elevated levels of distress in oncology patients. This evidence-based project demonstrated that APRNs have a positive impact on improving patient outcomes. Future research should be aimed at addressing additional nurse-sensitive outcomes including patient satisfaction, length of hospitalizations, compliance/adherence to treatment, and collaboration among care givers.

Summary

Applying evidence to improve patient outcomes is the scientific underpinning for doctoral-prepared advanced practice nurses. The Doctorate of Nursing Practice (DNP) Capstone Project should “address a complex practice, process, or systems problem within the student’s field of expertise, propose an evidence-based intervention to address that problem for a significant population, and use doctoral-level leadership skills to implement and evaluate the efficacy of the intervention” (National Organization of Nurse Practitioner Faculties, 2007). This Capstone Project identified and assessed patients who were experiencing an elevated level of distress as measured by the NCCN Distress Thermometer. The NCCN clinical practice guidelines for distress management were utilized to ensure that patients received current, evidence-based treatment.

In addition to understanding the scientific underpinnings of advanced practice nursing, doctoral-prepared advanced practice nurses must also utilize nursing theories and values to guide their decisions and actions. This evidence-based practice project supports the need to develop meaningful relationships, address unmet psychosocial needs, and practice according to our philosophy of patient care.

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Appendix A

Systematic Review Evidence Table Format [adapted with permission from Thompson, C. (2011). Sample evidence table format for a systematic review. In J. Houser & K. S. Oman (Eds.), *Evidence-based practice: An implementation guide for healthcare organizations* (p. 155). Sudbury, MA: Jones and Bartlett.]

| Author/Year Article Title and Journal | Database and Keywords Funding Source | Research Design and Level of Evidence | Study Aim/Purpose | Population Studied/Sample Size/Criteria/ Power | Methods/Study Appraisal/ Synthesis Methods | Primary Outcome Measures and Results | Author Conclusions/ Implications of Key Findings | Strengths/ Limitations | Comments |
|--|---|---|--|---|--|---|---|--|----------|
| Jacobsen, P. & Ransom, S. (2007). Implementation of NCCN distress management guidelines by member institutions. <i>Journal of the National Comprehensive Cancer Network</i> , 5, 99-102. | CINAHL: Psychological distress, cancer, distress thermometer. Funding: None | Level VI | Evaluate progress in implementing distress management guidelines by NCCN member institutions | N/A | Electronic survey to 18 NCCN institutions; responses received from 15. 83% response rate | 8 (53%) of institutions screened for distress. Reasons for not screening: considered unnecessary; not enough resources to screen or refer patients. | Limited progress on implementing distress management guidelines. All institutions did have mental health services available. Only 20% of member institutions screened all patients for distress | Limited to NCCN institutions; no community hospitals. Survey methodology; need to collect quantitative data from patients. | |

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|---|--|-----------------|--|---|
| <p>Jacobsen, P., Donovan, K., Trask, P., Fleishman, S., Zaobra, J., Baker, F., & Holland, J. (2005). Screening for distress in ambulatory cancer patients: A multicenter evaluation of the distress thermometer. <i>Cancer (7)</i>, 103, 1494-1502.</p> | <p>CINAHL, Keywords: screening, psychologic distress, cancer, distress thermometer. No funding source.</p> | <p>Level VI</p> | <p>Determine the optimal cutoff score on the distress thermometer (DT) for identifying clinically significant distress. Secondary objective: Explore demographic or clinical factors differentiated patients who scored above or below this cut off score.</p> | <p>380 patients at 5 participating institutions; all given a packet of self-report questionnaires: demographic/clinical form, DT, problem list, HADS, and BSI-18. Average age 56; 51% male, 49% female. 85% White. Average DT score 3.41.</p> |
|---|--|-----------------|--|---|

| | | | |
|--|--|--|---|
| <p>DT 0-10 score; Problem list with 34 commonly experienced problems grouped into 5 categories. Clinically significant distress on HADS ≥ 15. Clinically significant distress on BSI-18: Males ≥ 10; females ≥ 13.</p> | <p>Using the HADS as the criterion, DT cutoff score of 4 yielded a sensitivity of 77% and a specificity of 68%. Using the BSI-18 as the criterion, DT cutoff score of 4 yielded a sensitivity of 70% and a specificity of 70%. Chi-square analyses demonstrated only significant variable was gender (women more likely to have score > 4) and PS.</p> | <p>Optimal sensitivity and specificity was found utilizing a cutoff score of 4</p> | <p>Large sample size; limited diversity with regard to race, ethnicity, education, and socioeconomic status. No conclusions about clinical benefit to screening for distress.</p> |
|--|--|--|---|

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|--|--|------------------|---|---|
| <p>Mitchell, A. (2010). Short screening tools for cancer-related distress: A review and diagnostic validity meta-analysis. <i>Journal of the National Comprehensive Cancer Network</i>, 8(4), 487-494.</p> | <p>CINAHL. Keywords: psychosocial distress, cancer, distress thermometer.</p> | <p>Level I</p> | <p>Diagnostic validity of tools to identify distress in cancer and palliative settings.</p> | <p>45 potentially useful short and ultra-short tools were identified.</p> |
| <p>Vitek, L., Rosenzweig, M., & Stollings, S. (2007). Distress in patients with cancer: Definition, assessment, and suggested interventions. <i>Clinical Journal of Oncology Nursing</i> 11(3), 413-418.</p> | <p>CINAHL: Psychosocial distress, cancer, distress thermometer. No funding source.</p> | <p>Level VII</p> | <p>Reviewed nursing role and importance of for screening for distress</p> | <p>None</p> |

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| Systematic search of Medline/PubMed, Embase, SCOPUS and Web of Knowledge. Search limited to 2007-2009. Focused on diagnostic validity studies of tools to identify distress in cancer and palliative care settings. | Only 3 tools had diagnostic accuracy or validity in cancer settings with a primary focus on distress: HADS, Psychological Distress Inventory (PDI), and the General Health Questionnaire -12 (GHQ-12). | Most tools are used to diagnose depression and only a few have been validated in a cancer setting. Best evidence supports the NCCN Distress Thermometer (DT) | Searched only 2 years of data; didn't search CINAHL or Cochrane Library. | Good review of the multiple screening tools that have been used as well as the history of visual analog scales (VAS) |
| None | None | Supports routine, proactive use of DT in oncology patients | Review only | DT better than HADS or Beck Depression Inventory. Discusses role of oncology nurses |

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| <p>Shimizu, K., Ishibashi, Y., Umezawa, S., Izumi, H., Akizuki, N., Ogawa, A., Fujiwara, Y., Ando, M., Katsumata, N., Tamura, K., Kouno, T., Shimizu, C., Yonemori, K., Yunokawa, M., & Uchitomi, Y., (2010). Feasibility and usefulness of the distress screening program in ambulatory care in clinical oncology practice. <i>Psycho-Oncology</i>, 19, 718-725.</p> | <p>CINAHL: Psychosocial distress, cancer, distress thermometer. Funding source: Japanese Ministry of Health, Labor, and Welfare.</p> | <p>Level VI</p> | <p>Development of distress screening program in ambulatory care (DISPAC) program in Japan</p> | <p>491 patients completed the distress and impact thermometer (DIT) during the DISPAC period. 91.9% completed the DIT, results were positive in 37% of patients.</p> |
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| Compare the proportion of patients referred to a psycho-oncology service during the DISPAC period with the usual care period | DISPAC program useful for facilitating the care of patients with psychological distress. Only 25% of patients accepted the referral | 5.3% of patients who complete the DIT were treated by the psycho-oncology service compared to the usual number of patients (0.3%). $P < 0.001$ | Performed at a single center. Comparison group was not a control group. May have been some bias since only patients on study were referred to psych team. No demographic data. No data on patient impact. | What is the DIT? Is it different from the NCCN DT? Validity? Sensitivity? Specificity? None of these were reported. |
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| <p>Pasacreta, J., Kenefick, A., & McCorkle, R. (2008). Managing distress in oncology patients: Description of an innovative online educational program for nurses. <i>Cancer Nursing</i>, 31(6), 485-490.</p> | <p>CINAHL, Keywords: Psychosocial distress, cancer, distress thermometer. r. No funding source identified.</p> | <p>Level VI</p> | <p>Describes online education program for nurses to screen, recognize, manage, refer, and follow-up/evaluate distress in cancer patients</p> | <p>Reviewed and described participants and goals of program</p> |
| <p>Mitchell, A., Vahabzadeh, A., & Magruder, K. (2011). Screening for distress and depression in cancer settings: Ten lessons from 40 years of primary-care research. <i>Psycho-Oncology</i> (20), 572-584.</p> | <p>CINAHL, Keywords: psychosocial distress, cancer, distress thermometer. r. No funding source identified.</p> | <p>Level III</p> | <p>Data from primary care physicians and importance of partnering with primary care physicians to identify and treat distress in oncology patients</p> | <p>Multiple statistics on screening failure and treatment failure in primary care. Identified under & over detection, barriers to identification, acceptability of screening, importance of trust, frequency of visits, clinician confidence/skills, and training</p> |

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| None | None | Must provide educational resources & training for oncology nurses in order to screen and identify distress in oncology patients. | Good review of how to overcome traditional barriers to distress management. | Review the ICAN program (joint venture between NCCN & APOS). Still available? Future direction: does nurse education make a difference? |
| None | None | See population studied | Narrative | Good review of historical data and barriers as well as failures within primary care to detect and treat distress |

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| Spade, C. & Mulhall, M. (2010). Teaching psychosocial vital signs across the undergraduate nursing curriculum. <i>Clinical Simulating in Nursing</i> , 6(4), 143-151. | CINAHL; Keywords: psychosocial | Level VII | Theoretical framework, assessing patients holistically, therapeutic relationship, measuring psychosocial vital signs | None; not validated in clinical practice |
| Carlson, L., Waller, A., Mitchell, A. (2012). Screening for distress and unmet needs in patients with cancer: Review and recommendations. <i>Journal of Clinical Oncology</i> , 20(11), 1160-1177. | CINAHL; keywords: psychosocial distress, cancer, distress thermometer. No funding sources identified. | Level V | Literature review for psychometric distress screening tools | None |

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| None | None | Faculty implications | Not utilized in clinical practice; not validated in any patient population. | Incorporates nursing therapeutic relationship; has ideas regarding how to teach nurses how to assess for psychosocial stress |
| Authors utilized Embase, Web of Knowledge, and PubMed from inception to September 2011; studies were excluded if they were not validated | 30 articles | Important to include all stakeholders and frontline clinicians when screening for distress. | Excellent review of distress tools and needs assessments for specific populations as well as general populations | Discussed implementation, needs to screen unmet needs of underserved populations such as those with low income, ethnic minorities |

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| Fann, J., Ell, K. & Sharpe, M. (2012). Integrating psychosocial care into cancer services. <i>Journal of Clinical Oncology</i> , 30(11), 1178-1186. | CINAHL; keywords: psychosocial distress, cancer, distress thermometer. | Level V | Systematic identification of need, integrated delivery; model for services to meet psychosocial needs | None |
| Fulcher, C. & Gosselin-Acomb, T. (2007). Distress assessment: Practice change through guideline implementation. <i>Clinical Journal of Oncology Nursing</i> , 11(6), 817-821. | CINAHL. Keywords: psychosocial distress, cancer, distress thermometer. No funding sources identified. | Level VI | Pilot study in radiation oncology to implement NCCN DT | 57 Radiation oncology patients; total of 157 assessments |

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| None | None | Need evidenced-based approach on how to implement the psychosocial guidelines! | Great review of challenges and barriers. | How do we integrate psychosocial rounds and case management conferences? How do we partner with PCPs? |
| Delivered paper & pencil version of NCCN DT to patients at initial visit and treatment visits. | Mean baseline DT score 2.2. 8 patients had an increase in distress levels; 11 had a decrease in distress levels; all others remained the same. | DT was easy to use and referral process was simplified. Inconsistent use of DT by staff. Not a burden with nsg staff; built into normal clinical structure | Small, pilot study. No statistical significance. | Improved Press Ganey scores; patient perception was positive |

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| Preyde, M., & Synnott, E. (2009). Psychosocial intervention for adults with cancer: A meta-analysis. <i>Journal of Evidence-Based Social Work</i> , 6, 321-347. | CINAHL. Keywords: psychosocial distress. No funding source identified. | Level I | Psychosocial interventions for adults | Search terms: psychosocial, care, intervention, service, support, oncology, effectiveness, evaluation |
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| Articles from MEDLINE, CINAHL, PsycINFO, Social Sciences Citation Index, Social Services Abstracts, PubMed databases from 1999-2007. 27 studies included. | Systematic review of psychosocial interventions for adults with cancer | Limited RCT studies. Patient attrition problematic for many studies. Many studies have clinical significance. | Limited studies with quality ratings. Studies had small sample sizes. No statistically significant results of psychological or psychosocial well-being or adjustment. Majority of trials were breast cancer. Studies had poor quality of reporting methods and results. Articles dated. | |
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| <p>Carlson, L., Groff, S., Maciejewski, O., & Bultz, B. (2010). Screening for distress in lung and breast cancer outpatients: A randomized controlled trial. <i>Journal of Clinical Oncology</i>, 28(33), 4884-4890.</p> | <p>Cochrane Library. Keywords: psychosocial distress, cancer, distress thermometer. Funded by: Alberta Cancer Foundation & Canadian Cancer Society</p> | <p>Level II RCT</p> | <p>Determine best method of distress screening.</p> | <p>588 patients with breast cancer, 549 patients with lung cancer. 97.7% power to detect difference of 1 point (CI 95%, two-tailed test, standard deviation 3.0)</p> |
| <p>Fitch, M. (2011). Screening for distress: A role for oncology nursing. <i>Current Opinions in Oncology</i>, 23, 331-337.</p> | <p>MEDLINE: psychosocial distress, cancer. No funding source identified.</p> | <p>Level III</p> | <p>Review of literature on screening for distress and role of oncology nursing</p> | <p>None</p> |

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| Patients randomized to receive minimal screening, full screening, or full screening plus phone triage with referral | Best predictor of decreased anxiety and depression were patients that received full screening plus phone triage and referral | Routine screening is feasible in large cancer center; may reduce future distress levels, particularly when coupled with additional resources | High prevalence of distress in all groups at baseline. | |
| None | None | Critical to identify distress; many tools available. | Incorporated role of nurses | |

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| <p>Kendall, J., Glaze, K., Oakland, S., Hansen, J., & Parry, C. (2011). What do 1281 distress screeners tell us about cancer patients in a community cancer center? <i>Psycho-Oncology</i>, 20, 594-600.</p> | <p>CINHAL: psychosocial distress, cancer, distress thermometer. No funding sources.</p> | <p>Level VI</p> | <p>Data from 1,281 patients seen in a community cancer center. Reports intensity and frequency of distress.</p> | <p>Adult Medical and Radiation Oncology patients. Administered DT</p> |
| <p>Smith, J., Limesand, D., & Alikhan, A. (2011). Prevalence of psychosocial distress in a rural community oncology practice and impact of interventions. <i>Journal of Clinical Oncology</i>, 29, (abstract 9114)</p> | <p>CINHAL: psychosocial distress; cancer patients. No funding sources.</p> | <p>Level VI</p> | <p>268 patients completed the DT in outpatient oncology clinic.</p> | <p>Partnership with off-site local not-for-profit cancer wellness center to provide services</p> |

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| Utilized paper version of DT. Patients screened at initial visit and subsequent appts. Radiation patients screened weekly. | 32% had distress above threshold level. Worry was most common problem followed by financial issues. Emotional concerns were endorsed by 59% of sample | Distress screening can be accomplished in a community cancer center. | Done at St. Joseph's in Denver | |
| Outpatient oncology clinic | Mean distress level 4.18. 46% scored above the threshold (5 in this study). Only 10% accepted interventions at an off-site wellness center. | Prevalence of psychosocial distress higher in rural population than urban/academic outpatient clinics. Need to expand on-site cancer specific support groups. | Abstract at 2011 ASCO Meeting | |

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| Lowery, A., & Holland, J. (2011). Screening cancer patients for distress: Guidelines for routine implementation. <i>Community Oncology</i> , 8(11), 502-505. | MEDLINE: psychosocial distress; cancer. No funding sources. | Level V | Reviewed history of guidelines and routine screening as standard of care | Review of literature |
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NCCN DT is a rapid screening tool; easy to implement. Incorporate as standard of care into practice.

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| Mitchell, A., Lord, K., Slattery, J., Grainger, L., & Symonds, P. (2012). How feasible is implementation of distress screening by cancer clinicians in routine clinical care? Cancer, March 2012. | MEDLINE: psychosocial distress, cancer. No funding source. | Level VI | Clinicians asked to record their feedback after implementation of a distress screening program | 50 clinicians and 379 patients in a large academic hospital in the UK |
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| Used the Emotional Thermometer (ET) | <p>Clinicians believed screening was useful in 43% of assessments. Assisted staff in changing their clinical opinion about perceived distress levels. 37.5% clinicians felt that screening was impractical for routine use. 3 variables associated with high staff satisfaction: prior training, talking to patient about psychosocial issues, and improved detection of psychological problems.</p> | <p>33% of clinicians considered screening not useful/practical . >50% believed screening helped with communication and recognition of distress.</p> | Reviewed clinician and patient perspectives | |
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| <p>Absolom, K., Holch, P., Pini, S., Hill, K., Liu, A., Sharpe, M., Richardson, A., & Velikova, G. (2011). The detection and management of emotional distress in cancer patients: The views of health-care professionals. <i>Psycho-Oncology</i>, 20, 601-608.</p> | <p>PsychInfo: psychosocial distress. Funded by NCRI Supportive and Palliative Care Research Collaborative Grant, University of Leeds</p> | <p>Level VI</p> | <p>Explore the views of cancer professionals regarding their current roles and responsibilities in the detection and management of emotional distress, use of screening tools, and access to resources.</p> | <p>Interviews with 23 professionals (6 CNS, 8 oncologists, 4 surgeons, 5 ward sisters) from hospitals in the UK.</p> |
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| <p>Semi-structured interview schedule. Interview data analyzed using framework analysis to identify common themes.</p> | <p>Described how cancer professionals perceive their role and responsibilities in the detection and management of emotional distress. Attitudes towards the use of validated screening tools for detecting emotional distress. Access to specialist supportive services. Views of what currently limits the management of emotional distress.</p> | <p>All professionals acknowledged importance of detecting emotional distress in their patients. The CNSs were heavily relied upon to assess patients, provide emotional support, and refer to specialist services. Oncologists and surgeons did not consider emotional distress to be a key part of their role. Main barrier was lack of guidance on referral pathways to help staff decide when it was appropriate to refer, to which service, and how to access the services.</p> | <p>Study sample small; drawn from one geographic location in the UK.</p> | <p>Excellent study to support utilization of NCCN guidelines. All staff needed additional training on distress assessment and management. Need for standardized screening tools.</p> |
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| <p>Dudgeon, D., King, S., Howell, D., Green, E., Gibert, J., Hughes, E., Lalonde, B., Angus, H., & Sawka, C. (2012). Cancer care Ontario's experience with implementation of routine physical and psychological symptom distress screening. <i>Psycho-Oncology</i>, 21, 357-364.</p> | <p>PsycINFO: psychosocial distress, cancer. No funding source identified.</p> | <p>Level VI</p> | <p>QI initiative to implement routine distress screening with ESAS for cancer patients seen in 14 Regional Cancer Centers</p> | <p>Screening increased from 3.5% to 47%. Palliative care clinics screened 70 to 90% of patients. 85% of respondents felt it was worthwhile. 44 individuals participated in 14 interviews and 7 focus groups.</p> |
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| Used Edmonton Symptom Assessment System (ESAS) with a Calgary problem checklist as part of the recommended minimum standard for distress screening for patients in Canada. | Allow centers to examine the roles of different members of the health care team; reorganize work flow and responsibilities. Increase in educational activities for staff. Staff liked objective assessment. Algorithms and guides were developed to support further assessment and interventions. Demonstrated commitment to patient-centered care. | Routine screening is possible and creates a culture that is more patient-centered. | Canadian study; different distress tool | Currently evaluating feasibility of telephone survey. |
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| <p>Skrutkowski, M., Saucier, A., Eades, M., Swidzinski, M., Ritchie, J., Marchionni, C., & Ladouceur, M. (2008). Impact of a pivot nurse in oncology on patients with lung or breast cancer: Symptom distress, fatigue, quality of life, and use of healthcare resources. <i>Oncology Nursing Forum</i>, 35(6), 948-954.</p> | <p>CINAHL: psychosocial distress, cancer. No funding source identified.</p> | <p>Level II</p> | <p>RCT; patients randomized assigned to an intervention group with a pivot nurse and usual care by clinic nurses or to a control group with usual care only.</p> | <p>3 outpatient ambulatory oncology clinics in Quebec, Canada. 113 patients with lung cancer and 77 patients with breast cancer. Participants completed Symptoms Distress Scale as well as brief fatigue inventory and functional assessment of cancer therapy scale. Variables: symptom distress, fatigue level, QOL, healthcare usage.</p> |
| <p>Madden, J. (2006). The problem of distress in patients with cancer: More effective assessment. <i>Clinical Journal of Oncology Nursing</i>, 10(5), 615-619.</p> | <p>CINHAL: psychosocial distress, cancer. No funding source identified.</p> | <p>Level V</p> | <p>Overview of incidence, diagnosis, and treatment of emotional distress in patients with cancer</p> | <p>N/A</p> |

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| <p>PNO reviewed diagnosis, expected side effects and available resources with patients. Also assessed patients' needs and coping skills. Coordinated care across treatment modalities. Usual care consisted of symptom assessment and teaching but was not formally organized.</p> | <p>No significant difference in symptoms distress, fatigue, QOL, or healthcare usage. Statistically significant difference in distress over time based on cancer type; lung cancer group exhibited more distress than those in the breast cancer group $p=0.023$</p> | <p>Experienced nurses were able to offer as much care as PNO. Ambulatory nurses were oncology certified; PNOs did not have any oncology background and were not certified.</p> | <p>Small sample size (target was 400).</p> | <p>Pivot Nurse is similar to nurse navigator role in USA</p> |
| <p>N/A</p> | <p>N/A</p> | <p>Distress is common! Oncology nurses can become proficient at use of distress thermometer.</p> | <p>Limited statistics</p> | |

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| Grassi, L. (2011). Educational intervention in cancer outpatient clinics on routine screening for emotional distress: An observational study. <i>Psycho-Oncology</i> , 20(6), 669-674. | MEDLINE: psychosocial distress, cancer, distress thermometer. No funding source identified. | Level VI | Examine the effect of an educational model on distress screening in newly diagnosed cancer patients referred to a Psycho-Oncology Service (POS). | Distress and problems among newly diagnosed cancer patients who were referred based upon clinician judgment and after an education intervention on the DT. |
| Frost, G., Zevon, M., Gruber, M., Scrivani, R. (2011). Use of distress thermometer in an outpatient oncology setting. <i>Heath & Social Work</i> , 36(4), 293-297. | MEDLINE: distress thermometer. No funding source identified. | Level VI | Social worker pilot program to implement DT in head & neck cancer population | 763 patients screened; 19.6% had overall DT >4 or higher. Most frequently identified physical problems: fatigue, sleep, eating difficulties. Emotional problems: worry, nervousness, depression. |

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| Study 1: Physicians & nurses referred newly diagnosed patients by using their own judgment based on their experience with fatigue. Study 2: Educational intervention was developed. Patients with DT score >4 were referred to POS. | Implementatio n of the DT determined a higher and more accurate referral of patients. Acceptance of DT by staff was low. | 1/3 of patients referred based solely on clinician judgment did not show elevated levels of distress. Use of DT resulted in 79% increase in the accuracy of patients needing a referral. | Observational study; difficult to generalize | |
| Pilot program | NCCN DT implementatio n for all head & neck cancer patients | Distress scores pre and post intervention were not measured. | Conducted in single institution; may limit generalizabilit y | |

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| Hammonds, L. (2012). Implementing a distress screening instrument in a university breast cancer clinic: A quality improvement project. <i>Clinical Journal of Oncology Nursing</i> , 16, (5), 491-494. | MEDLINE: distress thermometer. No funding source identified. | Level VI | Pilot project done in an academic setting | 104 patients consented to participate. 55 patients were identified as having elevated level of distress (DT >4). 11 patients were referred for support. |
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| Pilot study | DT increased nurse identification of distress and referrals for support. | Nurses are positioned to identify distress among patients and make referrals for support. NCCN DT is an effective tool that can be used by nurses in busy settings. | Small sample in one institution. No measurement of distress pre and post intervention. | |
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| <p>Hurria, A., Li, D., Hansen, K., Patil, S., Gupta, R., Nelson, C., Lichtman, S., Tew, W., Hamlin, P., Zuckerman, E., Gardes, J., Limaye, S., Lachs, M., & Kelly, E. (2009). Distress in older patients with cancer. <i>Journal of Clinical Oncology</i>, 27(26), 4346-4351.</p> | <p>MEDLINE: distress thermometer. Funding source: Paul Beeson Career Development Award in Aging Research & American Society of Clinical Oncology Association of Specialty Professors Junior Development Award in Geriatric Oncology.</p> | <p>Level VI</p> | <p>Determine the prevalence of distress in older adults with cancer utilizing the DT. Determine whether predictors of distress could be identified using a brief geriatric assessment that captured information about the individual's functional status, comorbid medical conditions, psychological state, social support, and nutritional status.</p> | <p>Patients >65 in large academic setting. Patients completed the geriatric assessment prior to the appt. 245 patients completed the geriatric assessment. Of these, 214 patients also completed the DT.</p> |
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| <p>Geriatric Assessment & DT were utilized. All tumor types.</p> | <p>Mean DT score was 3; mean was 2. 41% of patients had a score of 4 or greater. Variables associated with higher levels of distress: needing assistance with ADLs ($P<.0001$); Karnofsky <70 ($P=.001$); having 3 or more comorbid conditions ($P=.047$), poor eyesight ($P=.002$), requiring services at home ($P=0.52$), and needing assistance to complete the geriatric assessment ($P=.003$).</p> | <p>DT and geriatric assessment were used to explore relationship between distress and several variables that predict morbidity and mortality in older adults. Helped to pinpoint the unique causes of distress that face older adults with cancer.</p> | <p>Convenience sample; primarily females with breast cancer. Limits generalizability. Did not discuss how chemotherapy could make DT score higher or lower. Data was self-reported.</p> | |
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| <p>Mertz, B., Bistrup, P., Johansen, C., Dalton, S., Deltour, I., Kehlet, H., & Kroman, N. (2012). Psychological distress among women with newly diagnosed breast cancer. <i>European Journal of Oncology Nursing</i>, 16(4), 439-443.</p> | <p>MEDLINE: psychosocial distress, cancer. No funding source identified.</p> | <p>Level VI</p> | <p>Determine prevalence of distress and investigate the related problems and characteristics of women with breast cancer who experienced psychological distress at the time of diagnosis.</p> | <p>Women with newly diagnosed breast cancer prior to breast surgery. 426 invited; 357 responded. 343 patients completed the DT and DT problem list.</p> |
| <p>Jacobsen, P. & Wagner, L. (2012). A new quality standard: The integration of psychosocial care into routine cancer care. <i>Journal of Clinical Oncology</i>, 30, 1-6.</p> | <p>CINAHL: psychosocial assessment, cancer. No funding sources identified.</p> | <p>Level VII</p> | <p>Review of standards, guidelines, and quality measurement</p> | <p>None</p> |

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| Cross-sectional data from a questionnaire. | 77% of women had a score >3; 43% scored >7. Mean distress score 5.4. Most frequent problems: worry & nervousness. Younger women (<50) had higher distress scores than older women (>50). No significant association between distress and social support. | 12% accepted a referral to psychological support, 54% asked for possible future referral, 30% refused referral. | Study done 1-2 days prior to surgery; may have resulted in increased number of women experiencing worry about the surgery. Many physical symptoms generally related to chemotherapy (fatigue, mouth sores) were reported prior to surgery. | Were these results expected pre-operatively? |
| None | None | Overview of accomplishments in standards of care, clinical practice guidelines and development of measurable indicators of quality | No review of patient outcomes | |

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| <p>Snowden, A., White, C., Christie, Z., Murray, E., McGowan, C., & Scott, R. (2011). The clinical utility of the distress thermometer: A review. <i>British Journal of Nursing</i>, 20(4), 220-227.</p> | <p>Medline: Psychosocial distress, distress thermometer. No funding sources identified.</p> | <p>Level I</p> | <p>Meta-analysis review to ascertain use of DT in clinical practice</p> | <p>Searched Medline, CINAHL, PsycINFO, Embase, ASSIA, British Nursing Index, AMED, CCTR and HMIC.</p> |
| <p>Steinberg, T., Roseman, M., Kasymjanova, G., Dobson, S., Lajeunesse, L., Dajczman, E., Kreisman, H., MacDonald, N., Agulnik, J., Cohen, V., Rosberger, Z., Chasen, M., & Small, D. (2009). Prevalence of emotional distress in newly diagnosed lung cancer patients. <i>Support Care Cancer</i>, 17, 1493-1497.</p> | <p>PsychInfo: psychosocial distress, cancer. Funded by an unrestricted grant from Sanofi-Aventis.</p> | <p>Level IV</p> | <p>Prevalence and associated symptoms of distress in newly diagnosed lung cancer patients</p> | <p>98 consecutive patients with newly diagnosed NSCLC or SCLC asked to completed the DT and ESAS as their first visit post-diagnosis and prior to any treatment. Mean age 63, M/F ratio 54:44. 81`% of patients had PS of 0-1.</p> |

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| Identified 40 stories that examined the function of the DT alone, together with the problem list, and other validated measures. | DT score of 4 is appropriate for distress screening; additional studies in oncology practice needed. | Limited studies available to review | | |
| ESAS is a numerical rating scale that assesses 9 physical and psychosocial symptoms common in cancer patients. DT cut off score was 4. | Level of distress not associated with age, sex, weight loss, or performance status. 51% of patients were identified as distressed by the DT at the time of diagnosis. Mean level of distress assessed by the DT was 3.64. Depression and nervousness were significant predictors of elevated distress score. | Prevalence of distress in lung cancer patients is high. Single-item DT is extremely useful instrument to rapidly identify elevated levels of distress. | Excellent review of literature; correlates closely to the Capstone project. Limited to lung cancer patients. Did not measure the impact of any interventions. | |

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| <p>Keir, S., Calhoun-Eagan, R., Swartz, J., Saleh, O., & Friedman, H. (2008). Screening for distress in patients with brain cancer using the NCCN's rapid screening measure. <i>Psycho-Oncology</i>, 17, 621-625.</p> | <p>PsycINFO: Psychosocial distress, cancer, distress thermometer. No funding source identified.</p> | <p>Level IV</p> | <p>Evaluated the extent and sources of distress in patients with brain cancer</p> | <p>75 patients diagnosed with a primary brain cancer. Inclusion criteria: at least age 18, ability to speak, read, and write English, Karnofsky score >70</p> |
| <p>Holland, J., & Alici, Y. (2010). Management of distress in cancer patients. <i>Journal of Supportive Oncology</i>, 8(1), 4-12.</p> | <p>CINAHL: Psychosocial distress, cancer. No funding sources identified.</p> | <p>Level VII</p> | <p>Overview of assessment and management of distress as well as common psychiatric disorders experienced by oncology patients.</p> | <p>None</p> |

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| Participants asked to complete written DT | 52% of patients had a DT score ≥ 4 . | Interventions should be designed to address worry, sadness, and depression seen in brain cancer patients. | Did not study any interventions | |
| None | None | Important to screen and identify patients at risk. Need further research to improve assessment and treatment of distress; especially among underserved population. | Nice review of psychiatric disorders. | |

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| Jacobsen, P., Holland, J., Steensma, D. (2012). Caring for the whole patient: The science of psychosocial care. <i>Journal of Clinical Oncology</i> , 30(12), 1-3. | CINAHL: psychosocial distress, cancer. No funding source identified. | Level VII | Summary of recent science; importance of screening and referral per the NCCN Guidelines. | None | None | None | Promotes greater knowledge and understanding of psychosocial care | Introduction for special oncology issue dedicated solely to distress screening | |
| Jacobsen, P. (2007). Screening for psychological distress in cancer patients: Challenges and opportunities. <i>Journal of Clinical Oncology</i> , 25(29), 4526-4527. | CINAHL: Psychosocial distress, cancer. No funding source identified. | Level VII | Need for adopting the NCCN guidelines | None | None | None | Recognizes need for RCTs | None | |
| Pincus, H. & Patel, S. (2009). Barriers to the delivery of psychosocial care for cancer patients: Bridging mind and body. <i>Journal of Clinical Oncology</i> , 27(5), 661-662. | CINAHL: Psychosocial distress, cancer. No funding source identified. | Level VII | Barriers to implementing the NCCN Guidelines. | None | None | None | Emphasizes need to identify patients, link them to appropriate resources, coordinate care, and follow up on care delivery | | |

| | | | | |
|--|---|-----------------|---|---|
| <p>Kadan-Lottick, N., Vanderwerker, L., Block, S., Zhang, B., & Prigerson, H. (2005). Psychiatric disorders and mental health service use in patients with advanced cancer. <i>Cancer</i>, 104, 2872-2881.</p> | <p>Medline: psychosocial distress, cancer. Funded by the National Institute of Mental Health.</p> | <p>Level VI</p> | <p>Determine the prevalence of diagnosable psychiatric illness and describe the mental health services received and predictors of service utilization in patients with advanced cancer.</p> | <p>251 patients with advanced cancer. Eligible patients: distant mets, primary therapy failure, nonpaid caregiver, age >20, English or Spanish speaking, adequate cognitive ability.</p> |
|--|---|-----------------|---|---|

| | | | | |
|---|--|---|--|--|
| Trained interviewers administered the DSM-IV modules for MDD, GAD, panic disorder, PTSD, and questionnaire regarding mental health service utilization. | 12% patients met criteria for major psychiatric condition; 28% had access a mental health intervention for psych diagnosis since the cancer diagnosis. 17% had talked to a mental health professional; 90% willing to receive treatment for emotional problems. Mental health services were not accessed by 55% of patients with major psychiatric conditions. | Advanced cancer patients experience major psych disorders at a prevalence similar to general population but affected individuals have a low rate of utilizing mental health services. Oncology providers should discuss mental health concerns with their patients. | Only 63% participation rate; potential for bias. | |
|---|--|---|--|--|

| | | | | |
|--|--|----------------|---|--|
| <p>Mitchell, A., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C., & Meader, N. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative care settings: A meta-analysis of 94 interview-based studies. <i>Lancet Oncology</i>, 12, 160-174.</p> | <p>Medline: Psychosocial distress, cancer. No funding source identified.</p> | <p>Level I</p> | <p>Quantitative summary of the prevalence of depression, anxiety, and adjustment disorders.</p> | <p>Searched Medline, PsycINFO, Embase, and Web of Knowledge sites for studies that examined depression, anxiety, and adjustment disorders in adults with cancer. Studies restricted to those using psych interviews.</p> |
|--|--|----------------|---|--|

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| 24 studies with 4007 patients were identified. Included 7 countries. | 16.5 % rate of depression, 15.4% rate of adjustment disorder, 9.8% rate of anxiety. No consistent correlates of depression; no effect of age, sex, clinical setting, cancer type or duration. | Depression and anxiety is less common in cancer patients than previously reported. | Not a longitudinal study. Did not examine stage of disease or duration of treatment. Only used interview-based studies. | |
|--|---|--|---|--|

| | | | | |
|--|--|----------|--|--|
| Swanson, J. & Koch, L. (2010). The role of the oncology nurse navigator in distress management of adult inpatients with cancer: A retrospective study. <i>Oncology Nursing Forum</i> , 37(1), 69-76. | Medline: Psychosocial distress, cancer. Funded by the National Cancer Institute. | Level VI | To determine if an ONN role as an intervention decreases the distress of adult inpatients with cancer. | Retrospective chart review, convenience sample of 55 inpatients. |
|--|--|----------|--|--|

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| <p>Nurses asked patients with cancer to rate their distress daily during their stays. Correlation studies and two-tailed t tests used to examine the relationship between the change in distress and the ONN intervention.</p> | <p>Patients seen by ONN had lower distress scores on dismissal ($p=.1046$). Statistically significant effect for patients <65 years ($p=.044$) and for patients who live in a rural setting ($p=.045$).</p> | <p>ONN can lower cancer-related distress scores, increase patient satisfaction? Increase QOL?</p> | <p>Retrospective chart audit; involved inpatients only.</p> | |
|--|---|---|---|--|

| | | | | |
|---|---|----------------|---|--|
| <p>Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. <i>Journal of the National Cancer Institute</i>, 101(21), 1464-1488.</p> | <p>CINAHL: Psychosocial distress, cancer, distress thermomete r. Funded by the Canadian Institutes for Health Research.</p> | <p>Level I</p> | <p>Examined the psychometric properties of existing tools used to screen patients for emotional distress.</p> | <p>Systematic search of Medline and PsycINFO databases. Keywords: depression, anxiety, screening, validation, and scale. Validation criteria: # of validation studies, # of participants, generalizability, reliability, quality of criterion measure, sensitivity, and specificity.</p> |
| <p>Pirl, W. (2004). Evidence report on the occurrence, assessment, and treatment of depression in cancer patients. <i>Journal of the National Cancer Institute</i>, 32-39.</p> | <p>CINAHL: psychosocial distress, cancer. No funding sources identified.</p> | <p>Level I</p> | <p>Literature review on depression in people with cancer: occurrence, assessment & treatment.</p> | <p>Systematic search PubMed, PsycINFO, CINAHL, and Biosis. Terms: neoplasms, depression, depressive disorder, antidepressant agents</p> |

| | | | | |
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| Yielded 106 validation studies that described 33 screening measures | Ultra short measures did best in palliative care settings; best short measures were ESDS & HADS, best long measures GHQ. 15 studies utilized the DT for a total of 4,088 participants. + Generalizability; moderate reliability, moderate criterion measures, moderate validity, Fair judgment. | Several generic and newly develop specific instruments met the high-quality criteria for use in emotional distress screening of cancer patients. Best to use the shortest tool that is easiest for clinician to interpret. | Reviewed a large number of tools; unable to judge the predictive validity of tools. Need more information on how screening affects long-term outcomes and QOL. | |
| 350 studies identified; limited by English language published between 1966 and 2001. | Majority of studies are cross-sectional prevalence studies. Prevalence rates vary widely; data suggests approx. 10-25% of cancer patients suffer from MDD. | DSM Manual Criteria for MDD is the standard assessment tool | No RCTs or alternative med studies. Need longitudinal studies to estimate the incidence of depression before cancer dx | |

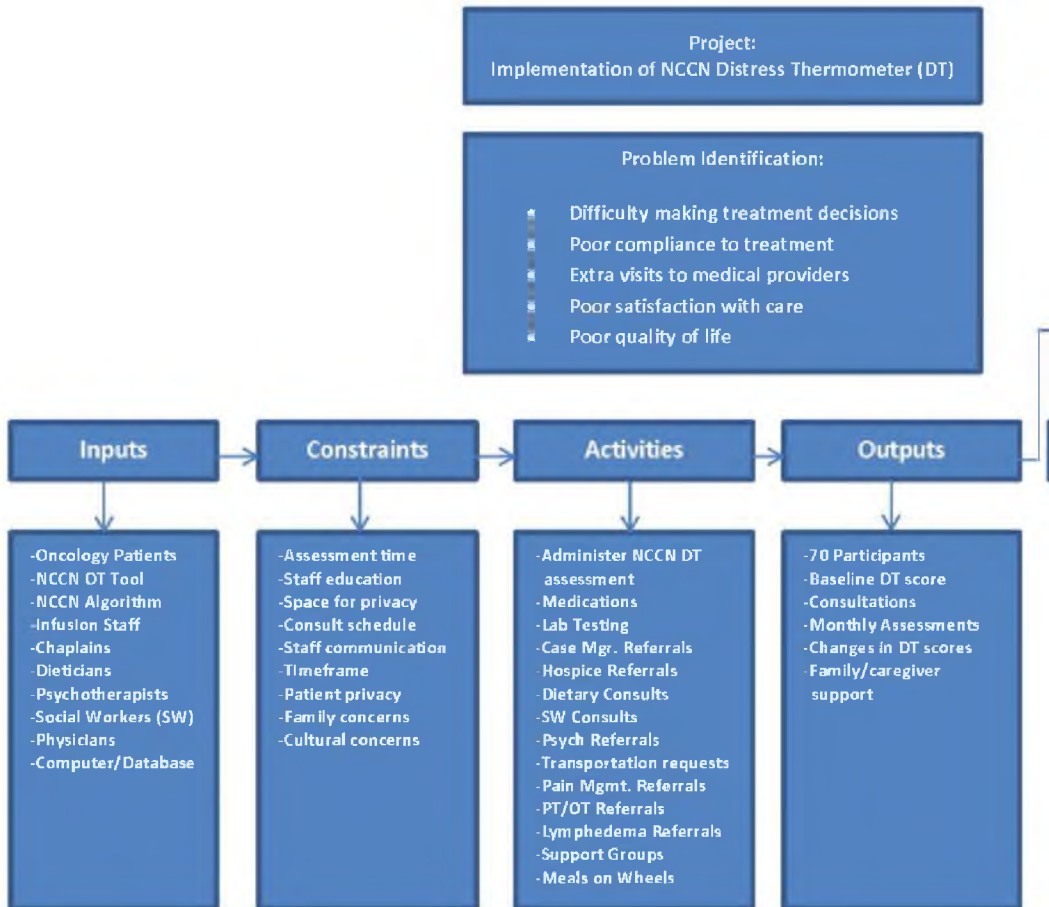
| | | | | |
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| Roth, A., Kornblith, A., Batel-Cooper, L., Peabody, E., Scher, H., & Holland, J. (1998). Rapid screening for psychologic distress in men with prostate cancer: A pilot study. <i>Cancer</i> , 82(10), 1904-1908. | CINAHL: distress thermometer. Supported by grants from PepsiCo Foundation and the T.J. Martell Foundation. | Level VI | Use rapid measure tool to identify patients with distress; compared HADS with DT | Median age 71, diagnosed a median of 4 yrs. DT cut off score 5, 28.6% score at or above this score. |
|--|--|----------|--|---|

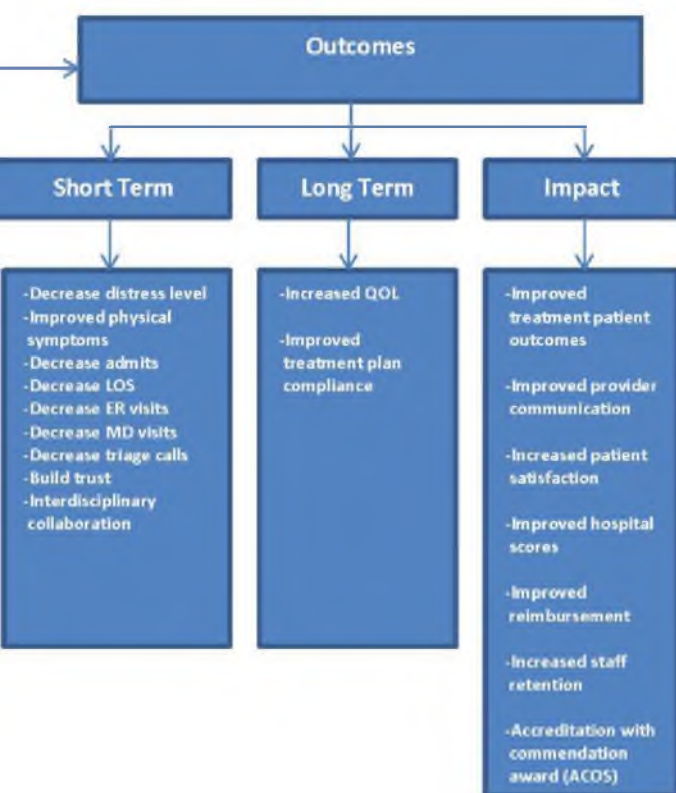
| | | | | |
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| 121 consecutive men with prostate cancer asked to complete the HADS and the DT | Patients with score >5 on DT or >15 on HADS were referred to psych MD for assessment; 31% of patients were evaluated by MD. Good correlation between elevated DT scores and presence of distress as measured by DSM criteria | Rapid screening approach was acceptable to patients and clinicians | No data on pre and post intervention | |
|--|--|--|--------------------------------------|--|

| | | | | |
|--|---|-----------------|--|--|
| <p>O'Sullivan, C., Bowles, K., Jeon, S., Ercolano, E., McCorkle, R. (2011). Psychological distress during ovarian cancer treatment: Improving quality by examining patient problems and advanced practice nursing interventions. <i>Nursing Research and Practice</i>, 1-14.</p> | <p>CINAHL: psychosocial distress, cancer, distress thermomete r. Funded by a grant through the NIH.</p> | <p>Level II</p> | <p>Single blind prospective RCT, designed to test the hypothesis that women with suspected ovarian cancer who received a specialized nursing intervention program would have greater improvement in QOL measures over time than women in an attention-control group.</p> | <p>145 subjects randomized following surgery. All screened for DT at baseline and prior to hospital discharge. DT cut-off score was 4.</p> |
|--|---|-----------------|--|--|

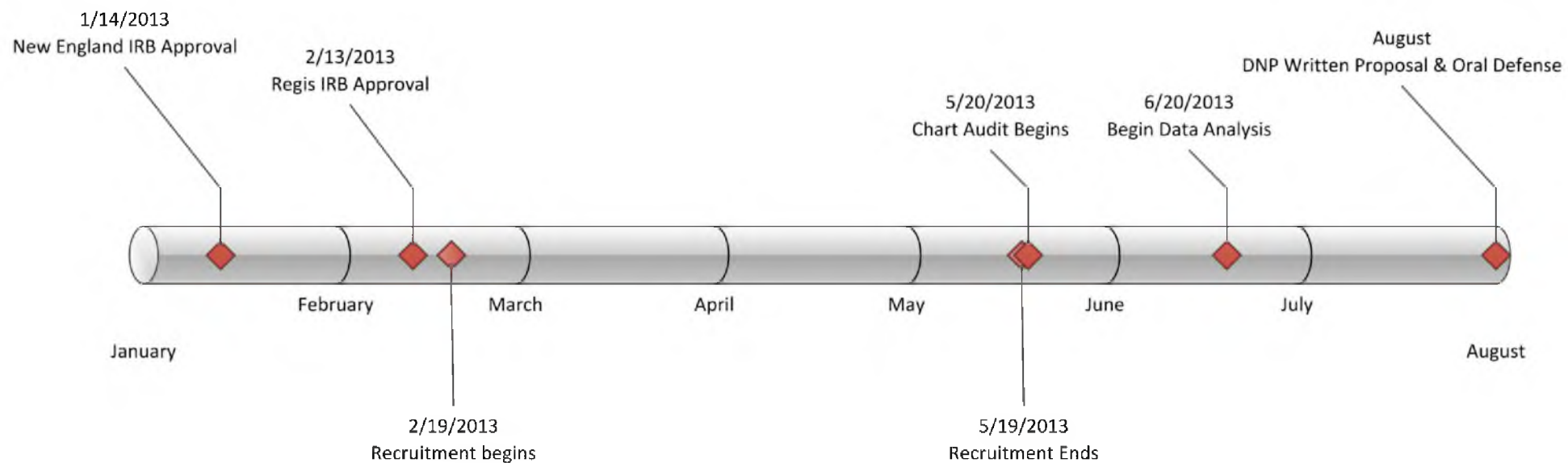
| | | | | |
|--|---|---|---|--|
| Secondary analysis of research records from a 6 month RCT included 32 women with primary ovarian cancer. All 18 received APN visits over 6 months. Demographic, clinical factors, patient problems and APN interventions obtained through content analysis and categorized via the Omaha system. | Clinically significant psych conditions were identified in 44% of participants who had elevated DT scores; they agreed to psych referral. High distress subjects who refused mental health intervention had more income and housing problems than the other subjects, received the fewest interventions at baseline and received progressively more interventions throughout the study. | Highly distressed women not psychologically ready to work through emotional consequences of cancer at treatment onset may obtain support from APNs to manage cancer problems as they arise. | Retrospective chart audit, ovarian cancer population only. Sample lacked diversity. | |
|--|---|---|---|--|

Appendix B: Logic Model





Appendix C: Project Timeline



Appendix D

February 2013

Dear Participant:

My name is Denise Sartz. I am a student at Regis University in the Doctorate of Nursing Program under the supervision of Dr. Diane Ernst. You are invited to participate in an evidence-based project entitled: Screening for Distress in Ambulatory Oncology Patients: The COPE Project. You have been asked to be a part of this project because you have been diagnosed with cancer and you are receiving treatment at Cheyenne Regional Medical Center. The purpose of this project is to identify new programs and services that will improve care for oncology patients receiving their treatment at Cheyenne Regional Medical Center. This project has been approved by Regis University's Institutional Review Board as well as Cheyenne Regional Medical Center.

If you agree to participate in this project, I will ask you to complete a written checklist called a "distress thermometer" at least monthly during one of your visits to the ambulatory infusion center at Cheyenne Regional Medical Center. The checklist will take approximately 5 minutes to complete. You will also meet with an advanced practice nurse at each visit to review the results of the checklist. If you are experiencing distress during any part of your treatment, you will be offered additional care and support which may include: a chaplain, dietician, financial counselor, mental health professional, or other specialist. Your participation will last approximately 3 months. If you need help with distress after the project has been completed you will continue to receive treatment and support.

Your participation in this project is confidential. None of the information will identify you by name. All records will be stored in a locked cabinet which can be only be accessed by me or a co-investigator. The results of this project may be presented at meetings or in publications; however, your identity will never be disclosed in those presentations or publications.

There are no direct costs to you for participating in this project. You or your insurance company will be charged for any medical care and/or hospitalizations related to your cancer treatment. You will not be paid for taking part in this project.

Please take your time making a decision and feel free to discuss it with your family and friends. If you have additional questions or concerns please contact me at: 307-633-6875 or 307-274-7827. You can also reach me via email at: denise.sartz@crmcwy.org. You can also contact my project advisor, Dr. Diane Ernst, at 303-964-5768 any time during this project.

Sincerely,

Denise A. Sartz, MS, AOCNP, FNP-C

Appendix E

December 12, 2012

Denise Sartz
Cheyenne Regional Med Ctr
214 E. 23rd St
Cheyenne, Wyoming 82001

On behalf of the National Comprehensive Cancer Network® (NCCN®), I am writing to grant you permission to reproduce the **Distress Thermometer Screening Tool Figure (DIS-A)** from the **NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.2.2013** as described in your original request for use with your patients. Permission is granted solely for the purposes described herein, which you represent and warrant to be for non-promotional educational use only. The following qualifications also apply to the permission granted by this letter:

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

Sincerely,

John Arnao

John T. Arnao
Business Development Coordinator
National Comprehensive Cancer Network

Additional Information on the NCCN Guidelines:

The NCCN Guidelines® - the recognized standard for clinical policy in oncology - are the most comprehensive and most frequently updated clinical practice guidelines available in any area of medicine. Covering 97 percent of all patients with cancer and updated on a continual basis, the NCCN Guidelines are developed through an explicit review of the evidence integrated with expert medical judgment and recommendations by multidisciplinary panels from NCCN Member Institutions. There are 44 individual panels, comprising nearly 900 clinicians and oncology researchers from the 21 NCCN Member Institutions and their affiliates. Specific treatment recommendations are implemented through performance measurement. NCCN Guidelines Panels address cancer detection, prevention and risk reduction, workup and diagnosis, treatment, and supportive care.

NCCN Guidelines have become the most widely used guidelines in oncology practice and have been requested by cancer care professionals in more than 115 countries. There has also been substantial international interest in translating the NCCN Guidelines into a variety of languages. Select NCCN Guidelines have been translated into Chinese, German, Italian, Japanese, Korean, Polish, Portuguese, Russian, Spanish, and Turkish.

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Appendix F
Comprehensive Oncology Patient Experiences (COPE) Assessment

Step Two: Please indicate if any of the following has been a problem for you in the past week including today.

Patient ID: _____

Date: _____

Step One: Please circle the number below that best describes how much distress you have been experiencing in the past week including today.

| | |
|------------------|----|
| Extreme Distress | 10 |
| | 9 |
| | 8 |
| | 7 |
| | 6 |
| | 5 |
| | 4 |
| | 3 |
| | 2 |
| | 1 |
| No Distress | 0 |

| YES | NO | Practical Problems |
|--------------------------|--------------------------|---------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Child Care |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/Financial |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions |

| YES | NO | Family Problems |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues |

| YES | NO | Emotional Problems |
|--------------------------|--------------------------|--------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Depression |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry |
| <input type="checkbox"/> | <input type="checkbox"/> | Lost of interest in usual activities |

| YES | NO | Spiritual/Religious Concerns |
|--------------------------|--------------------------|----------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Defining/finding meaning in life |
| <input type="checkbox"/> | <input type="checkbox"/> | Defining/finding hope |
| <input type="checkbox"/> | <input type="checkbox"/> | Finding peace of mind |
| <input type="checkbox"/> | <input type="checkbox"/> | Spiritual resources |
| <input type="checkbox"/> | <input type="checkbox"/> | Relaxation |
| <input type="checkbox"/> | <input type="checkbox"/> | Meeting similar patients |

| YES | NO | Physical Problems |
|--------------------------|--------------------------|------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Diarrhea |
| <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| <input type="checkbox"/> | <input type="checkbox"/> | Feeling Swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration |
| <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| <input type="checkbox"/> | <input type="checkbox"/> | Nausea/Vomiting |
| <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested |
| <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |

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Appendix G



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Distress Management

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Continue



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NCCN Guidelines Version 2.2013 Panel Members Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

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£ Supportive Care including Palliative, Pain
management, Pastoral care and Oncology social work
ξ Bone Marrow Transplantation
Nursing
† Medical oncology
¶ Surgery/Surgical oncology
¥ Patient Advocacy
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Continue

[NCCN Guidelines Panel Disclosures](#)

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NCCN Guidelines Version 2.2013 Table of Contents

Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

[NCCN Distress Management Panel Members](#)

[Summary of the Guidelines Updates](#)

Key Terms:

- [Distress \(DIS-1\)](#)
- [Definition of Distress in Cancer \(DIS-2\)](#)
- [Standards of Care for Distress Management \(DIS-3\)](#)
- [Overview of Evaluation and Treatment Process \(DIS-4\)](#)
- [Expected Distress Symptoms \(DIS-5\)](#)
- [Screening Tools for Measuring Distress \(DIS-A\)](#)
- [Psychosocial Distress Patient Characteristics \(DIS-B\)](#)
- [Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)
- [Social Work and Counseling Services \(DIS-20\)](#)
- [Chaplaincy Services \(DIS-21\)](#)
- [Recommendations for Implementation of Standards and Guidelines \(DIS-28\)](#)
- [Recommended Readings for Implementation of Programs That Integrate Psychosocial Care Into the Routine Care of Patients With Cancer \(DIS-28\)](#)
- [Institutional Evaluation of Standards of Care \(DIS-29\)](#)
- [For End of Life Issues. See the NCCN Guidelines for Palliative Care](#)
- [For Cancer Pain. See the NCCN Guidelines for Adult Cancer Pain](#)

Clinical Trials: The NCCN believes that the best management for any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

To find clinical trials online at NCCN member institutions, [click here: nccn.org/clinical_trials/physician.html](#)

NCCN Categories of Evidence and Consensus: All recommendations are Category 2A unless otherwise specified.

See [NCCN Categories of Evidence and Consensus](#)

The NCCN Guidelines® are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2012.



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NCCN Guidelines Version 2.2013 Updates Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

Updates in version 2.2013 of the NCCN Guidelines for Distress Management from Version 1.2013 include:

- The “Recommended Readings for Implementation of Programs that Integrate Psychosocial Care into the Routine Care of Patients with Cancer” reference list was moved from the Discussion to the algorithm. ([DIS-28](#))
- The Discussion text was updated to correspond to the changes in the algorithm. ([MS-1](#))

Updates in version 1.2013 of the NCCN Guidelines for Distress Management from Version 3.2012 include:

[DIS-5](#)

- Under Interventions: “Spiritual support” was added.

[DIS-A](#) Screening Tools for Measuring Distress

- “Substance abuse” was added to the list of Physical Problems.

[DIS-B](#) (Psychosocial Distress Patient Characteristics)

- Periods of Increased Vulnerability: The second bullet changed to “During diagnostic workup”.

[DIS-10](#) (Mood Disorder)

- Danger to self or others: The third bullet changed to “Consider removing ~~sharp~~ dangerous objects”.

[DIS-14](#) (Adjustment Disorder)

- Danger to self or others: The third bullet changed to “Consider removing ~~sharp~~ dangerous objects”.

[DIS-18](#) (Substance-Related Disorder/Abuse)

- Fourth column: The recommendation changed to “Referral to specialized treatment programs”.

[DIS-19](#) (Personality Disorder)

- Evaluation: The following bullets were clarified as follows, “Threatening behavior; Dramatic/histrionic behavior; Demanding behavior”.

[DIS-24](#) (Chaplaincy Services: Guilt)

- Footnote “h”: “Referral to clergy of person’s faith” changed to “Consider referral to community religious resource”.



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

"DISTRESS"

Term "distress" was chosen because it:

- Is more acceptable and less stigmatizing than "psychiatric," "psychosocial," or "emotional"
- Sounds "normal" and less embarrassing
- Can be defined and measured by self-report.

Definition of Distress in Cancer (DIS-2)

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.



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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

DEFINITION OF DISTRESS IN CANCER

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

[Standard of Care for Distress Management \(DIS-3\)](#)

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.



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[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

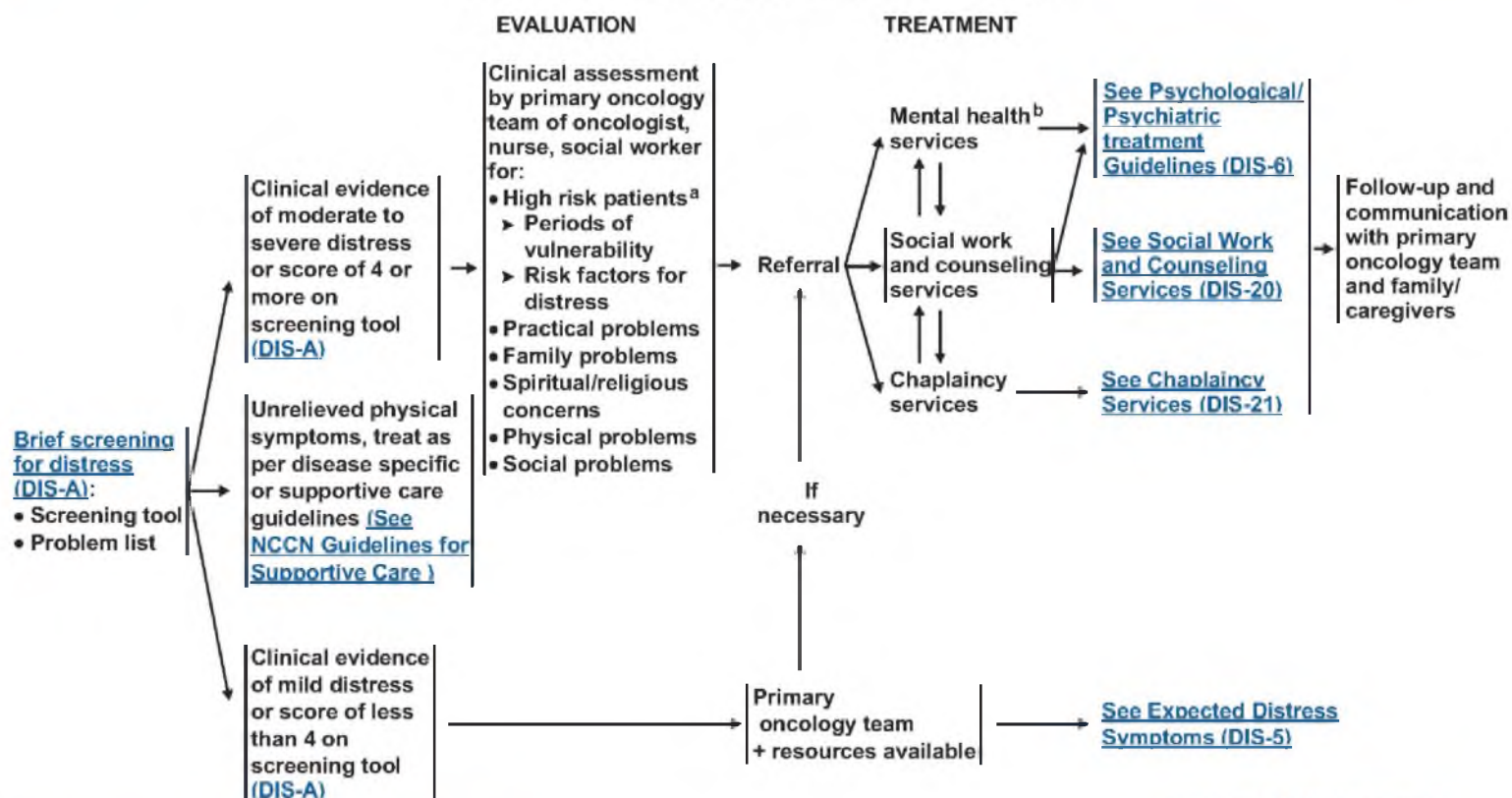
STANDARDS OF CARE FOR DISTRESS MANAGEMENT

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.
- Screening should identify the level and nature of the distress.
- All patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated especially with changes in disease status (ie, remission, recurrence, progression).
- Distress should be assessed and managed according to clinical practice guidelines.
- Interdisciplinary institutional committees should be formed to implement standards for distress management.
- Educational and training programs should be developed to ensure that health care professionals and certified chaplains have knowledge and skills in the assessment and management of distress.
- Licensed mental health professionals and certified chaplains experienced in psychosocial aspects of cancer should be readily available as staff members or by referral.
- Medical care contracts should include reimbursement for services provided by mental health professionals.
- Clinical health outcomes measurement should include assessment of the psychosocial domain (eg, quality of life and patient and family satisfaction).
- Patients, families, and treatment teams should be informed that management of distress is an integral part of total medical care and provided with appropriate information about psychosocial services in the treatment center and the community.
- Quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

OVERVIEW OF EVALUATION AND TREATMENT PROCESS



^aSee Psychosocial Distress Patient Characteristics (DIS-B).

^bPsychiatrist, psychologist, advanced practice clinicians, and/or social worker.

[Refer to NCCN Guidelines Table of Contents for Supportive Care Guidelines.](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

EXPECTED DISTRESS SYMPTOMS

- Patients at increased risk of vulnerability to distress^a
- Signs and symptoms of fear and worry about the future and uncertainty
 - Concerns about illness
 - Sadness about loss of usual health
 - Anger, feeling out of control
 - Poor sleep
 - Poor appetite
 - Poor concentration
 - Preoccupation with thoughts of illness and death
 - Disease or treatment side effects
 - Concerns about social role (ie, as father, mother)

INTERVENTIONS

- Clarify diagnosis, treatment options and side effects
 - Be sure patient understands disease and treatment options
 - Refer to appropriate patient education materials (eg, NCCN Treatment Summaries for Patients)
- Educate patient that points of transition may bring increased vulnerability to distress
- Acknowledge distress
- Build trust
- Ensure continuity of care
- Mobilize resources
- Consider medication to manage symptoms:
 - Analgesics ([See NCCN Adult Cancer Pain Guidelines](#))
 - Anxiolytics
 - Hypnotics
 - Antidepressants
- Support groups and/or individual counseling
- Family support and counseling
- Relaxation, meditation, creative therapies (eg, art, dance, music)
- Spiritual support
- Exercise

RE-EVALUATION

Monitor functional level and reevaluate at each visit

Stable or diminished distress

Continue monitoring and support

Increased or persistent distress

[See Distress Score ≥ 4 or moderate to severe distress \(DIS-4\)](#)

^a[See Psychosocial Distress Patient Characteristics \(DIS-B\)](#).

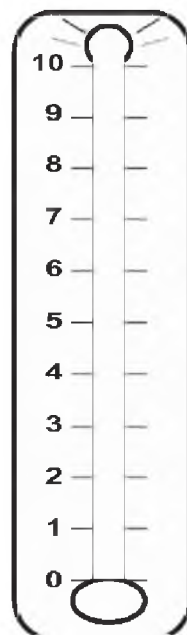
Note: All recommendations are category 2A unless otherwise indicated.

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SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems

- ☐ ☐ Child care
- ☐ ☐ Housing
- ☐ ☐ Insurance/financial
- ☐ ☐ Transportation
- ☐ ☐ Work/school
- ☐ ☐ Treatment decisions

Family Problems

- ☐ ☐ Dealing with children
- ☐ ☐ Dealing with partner
- ☐ ☐ Ability to have children
- ☐ ☐ Family health issues

Emotional Problems

- ☐ ☐ Depression
- ☐ ☐ Fears
- ☐ ☐ Nervousness
- ☐ ☐ Sadness
- ☐ ☐ Worry
- ☐ ☐ Loss of interest in usual activities

- ☐ ☐ Spiritual/religious concerns

Other Problems: _____

YES NO Physical Problems

- ☐ ☐ Appearance
- ☐ ☐ Bathing/dressing
- ☐ ☐ Breathing
- ☐ ☐ Changes in urination
- ☐ ☐ Constipation
- ☐ ☐ Diarrhea
- ☐ ☐ Eating
- ☐ ☐ Fatigue
- ☐ ☐ Feeling Swollen
- ☐ ☐ Fevers
- ☐ ☐ Getting around
- ☐ ☐ Indigestion
- ☐ ☐ Memory/concentration
- ☐ ☐ Mouth sores
- ☐ ☐ Nausea
- ☐ ☐ Nose dry/congested
- ☐ ☐ Pain
- ☐ ☐ Sexual
- ☐ ☐ Skin dry/itchy
- ☐ ☐ Sleep
- ☐ ☐ Substance abuse
- ☐ ☐ Tingling in hands/feet



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

PSYCHOSOCIAL DISTRESS PATIENT CHARACTERISTICS^c

PATIENTS AT INCREASED RISK FOR DISTRESS^d

- History of psychiatric disorder/substance abuse
- History of depression/suicide attempt
- Cognitive impairment
- Communication barriers^e
- Severe comorbid illnesses
- Social issues
 - Family/caregiver conflicts
 - Inadequate social support
 - Living alone
 - Financial problems
 - Limited access to medical care
 - Young or dependent children
 - Younger age; woman
 - History of abuse (physical, sexual)
 - Other stressors
- Spiritual/religious concerns
- Uncontrolled symptoms

PERIODS OF INCREASED VULNERABILITY

- Finding a suspicious symptom
- During diagnostic workup
- Finding out the diagnosis
- Awaiting treatment
- Change in treatment modality
- End of treatment
- Discharge from hospital following treatment
- Transition to survivorship
- Medical follow-up and surveillance
- Treatment failure
- Recurrence/progression
- Advanced cancer
- End of life

^cFor site-specific symptoms with major psychosocial consequences, see Holland, JC, Greenberg, DB, Hughes, MD, et al. Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management. (Based on the NCCN Distress Management Guidelines). IPOS Press, 2006. Available at www.apos-society.org.

^dFrom the NCCN Palliative Care Clinical Practice Guidelines in Oncology. Available at www.nccn.org.

^eCommunication barriers include language, literacy, and physical barriers.

Note: All recommendations are category 2A unless otherwise indicated.

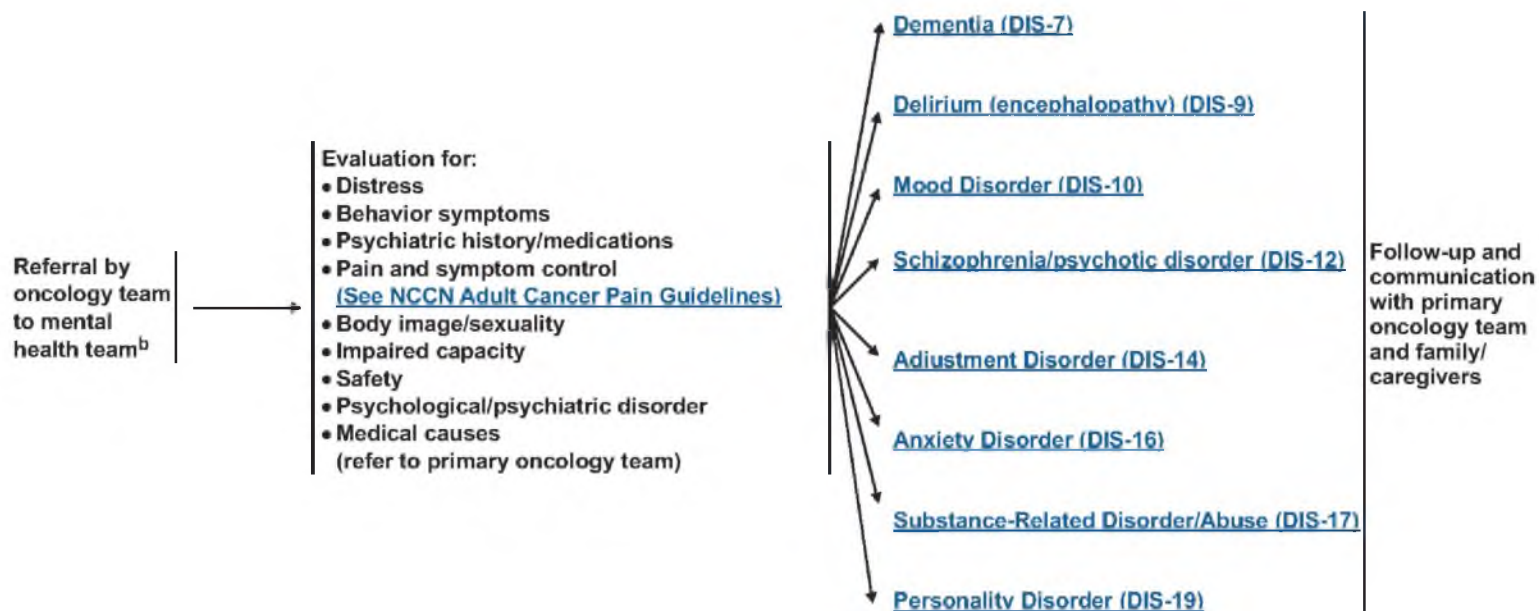
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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

PSYCHOLOGICAL/PSYCHIATRIC TREATMENT GUIDELINES



^bPsychiatrist, psychologist, advanced practice clinicians, and/or social worker.

[For End of Life Issues. See NCCN Palliative Care Guidelines](#)

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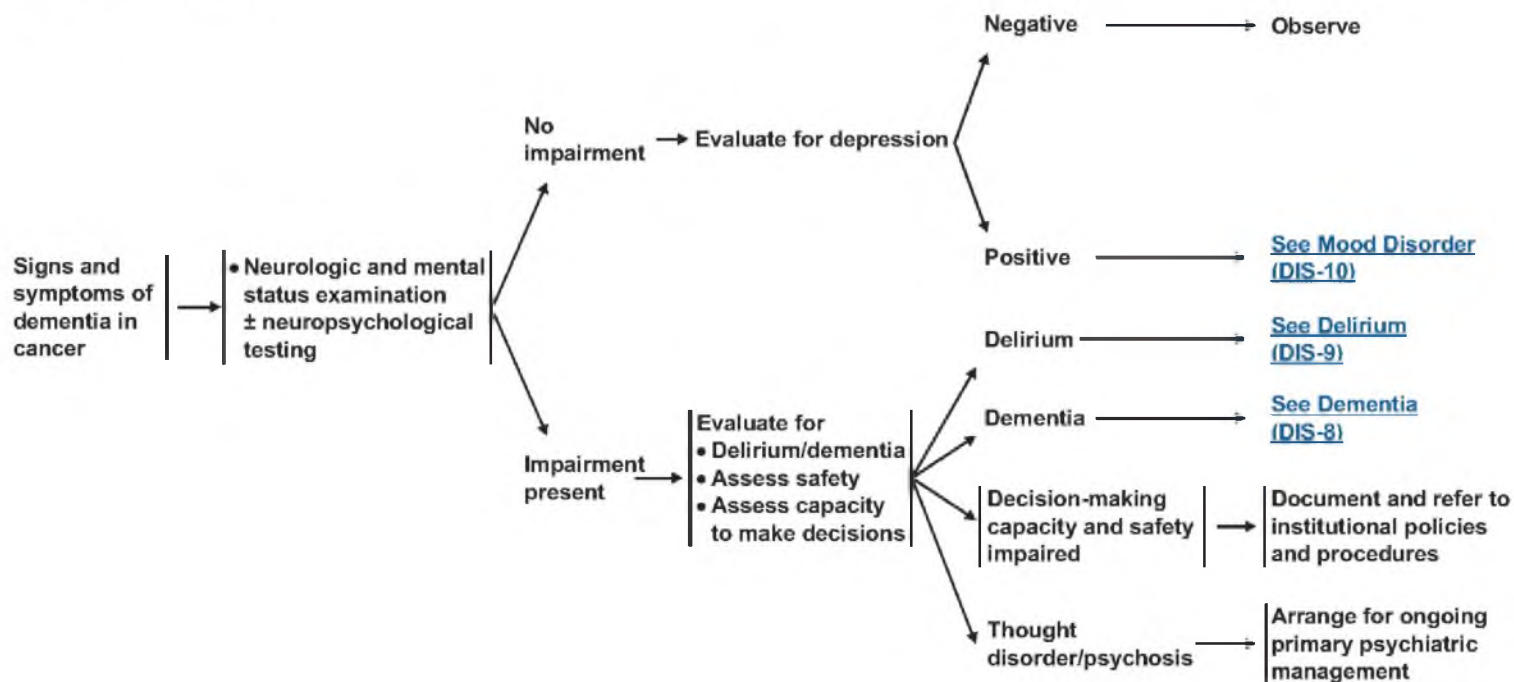


NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

DEMENTIA (ICD-10 codes: F00-F03)

EVALUATION



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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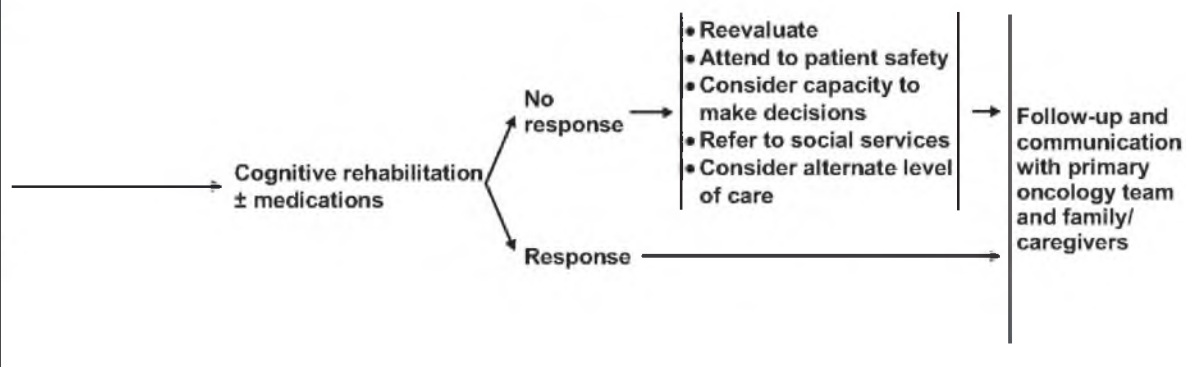
[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

DEMENTIA (continued)
(ICD-10 codes: F00-F03)

TREATMENT

FOLLOW-UP

Evaluation, diagnostic studies,
and modification of factors
related to:
• Cancer
• Treatment
• Medications
• Medical causes
• Withdrawal states
• Pain, fatigue, sleep disorders,
cognitive impairment, and
other symptoms
Assess safety
Assess family/caregiver
resources



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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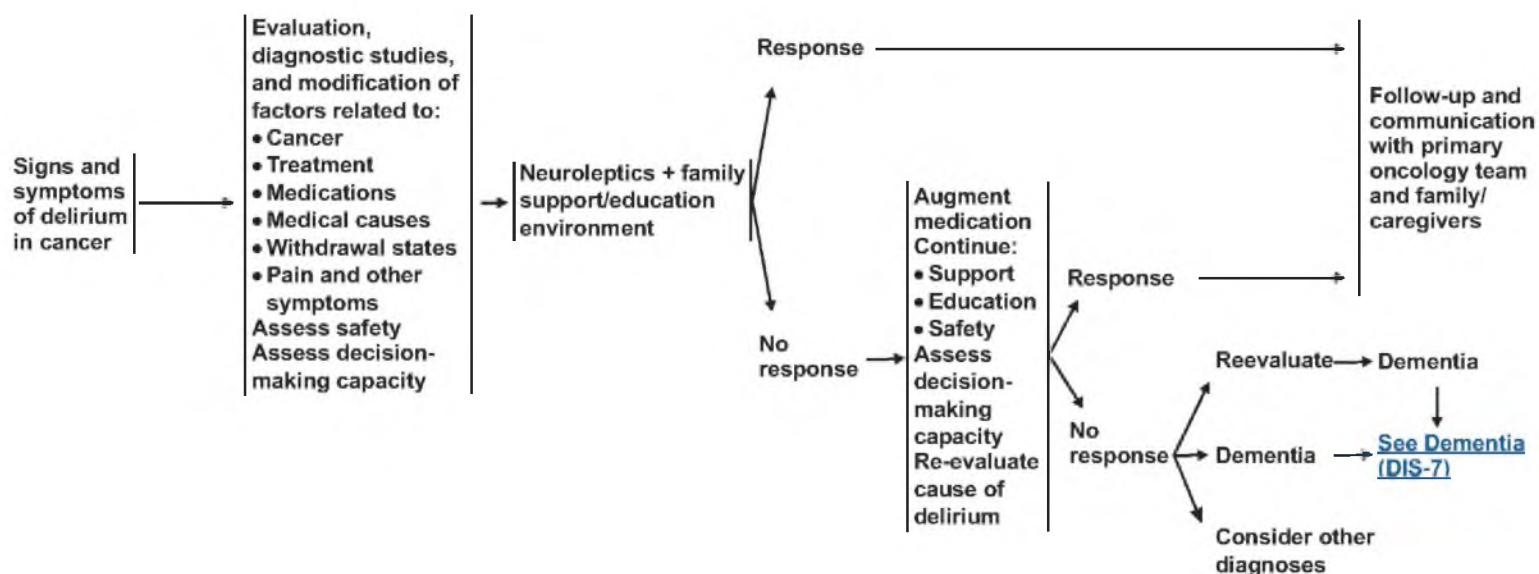
[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

DELIRIUM
(Encephalopathy)
(ICD-10 code: F05)

EVALUATION

TREATMENT

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

MOOD DISORDER
 (ICD-10 codes: F34, F38, F39)

EVALUATION

Evaluation, diagnostic studies, and modification of factors related to:

- Cancer
- Treatment
- Medications
- Medical causes
- Withdrawal states
- Pain
- Fatigue
- Insomnia
- Anorexia
- Anhedonia
- Decreased interest in activities
- Wish to die
- Suicidal thoughts
- Mood swings

Consider psychosocial and spiritual concerns
 Assess decision-making capacity
 Assess safety

TREATMENT

- Psychotherapy
- Antidepressant (category 1) ± anxiolytic
- Psychiatric follow-up for hospitalized patients and outpatients
- Consider referral to social work services or chaplaincy services
[See Social work and Counseling services \(DIS-20\) or Chaplaincy services \(DIS-21\)](#)

FOLLOW-UP

No/partial response → [See Mood Disorder \(DIS-11\)](#)
 Response → Follow-up and communication with primary oncology team and family/caregivers

Signs and symptoms of mood disorders in cancer:

- Mood disorder related to medical illness
- Major depression
- Dysthymia
- Bipolar disorder

No danger to self or others →

Danger to self or others →

Assure patient safety:

- Consider psychiatric consultation
- Increase monitoring
- Consider removing dangerous objects
- Consider hospitalization

Psychiatric treatment and follow-up for hospitalized and outpatients

[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

Note: All recommendations are category 2A unless otherwise indicated.

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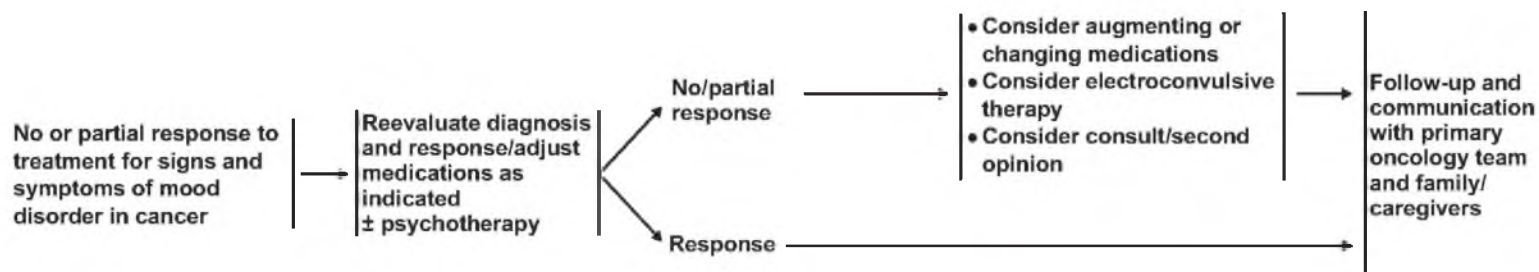
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[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

MOOD DISORDER (continued) **EVALUATION**
(ICD-10 codes: F34, F38, F39)

TREATMENT

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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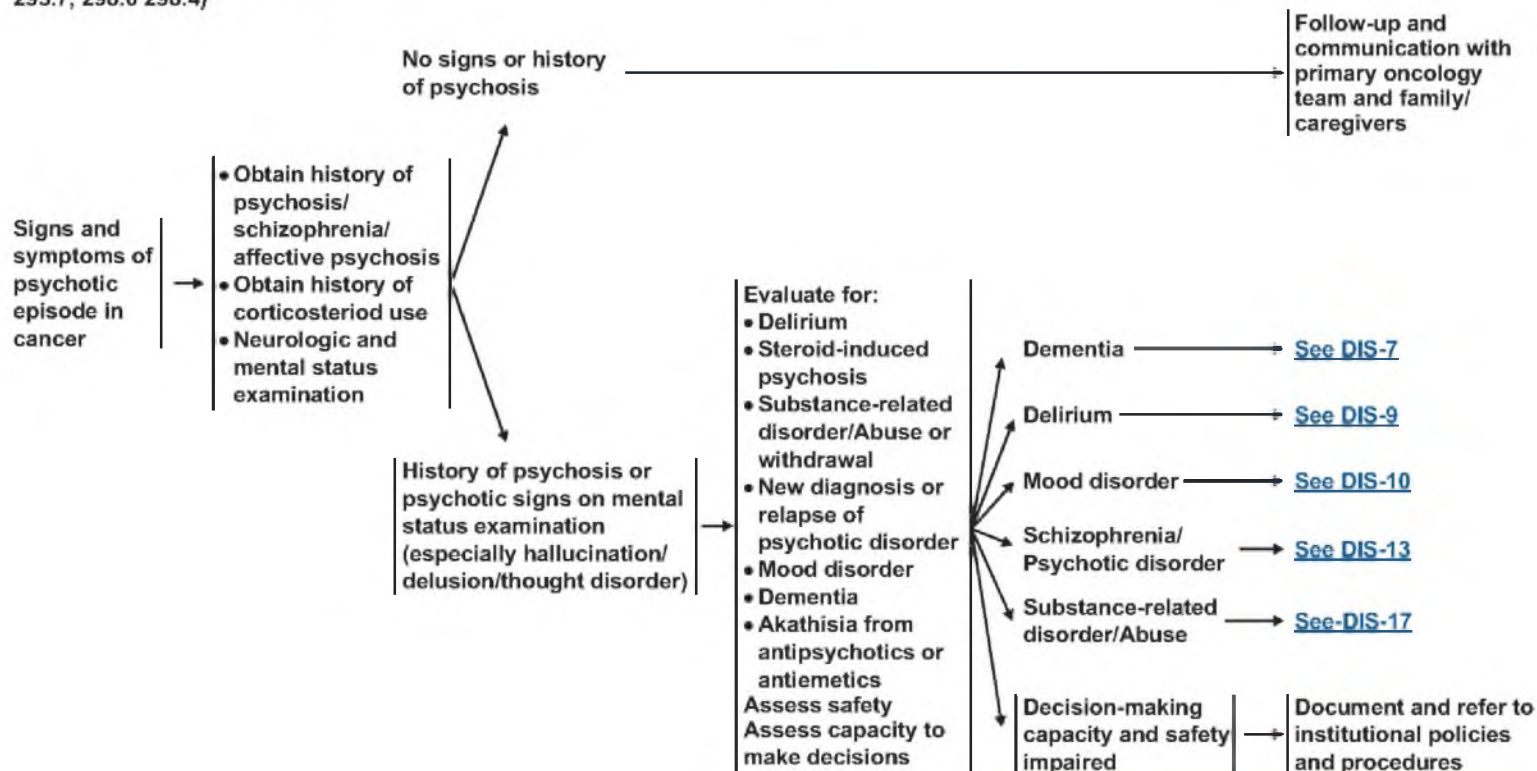
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Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

SCHIZOPHRENIA/PSYCHOTIC DISORDER
 (ICD-10 codes: 295.0, 296.0, 298.8, 298.9, 295.7, 298.0 298.4)

EVALUATION



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

Note: All recommendations are category 2A unless otherwise indicated.
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[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

SCHIZOPHRENIA/PSYCHOTIC DISORDER
(ICD-10 codes: 295.0, 296.0, 298.8, 298.9,
295.7, 298.0 298.4)

TREATMENT

FOLLOW-UP

Evaluation, diagnostic studies, and
modification of factors related to:

- Cancer
 - Treatment
 - Medications (particularly steroids)
 - Delirium
 - Withdrawal states or substance abuse
 - New diagnosis of psychotic disorder
 - Relapse of psychotic disorder
(eg, not taking maintenance anti-psychotic medications)
 - Dementia
- Assess safety
Assess capacity to make decisions
Assess family/caregiver resources
including inpatient psychiatry
hospitalization and community mental
health team

- Secure safety
- Consider anti-psychotic medications (Urgently administer if necessary.)
- Consider medications for mood
- Consider transfer to psychiatric unit/hospital
- Consider role of electroconvulsive therapy in psychotic depression/mania, catatonia

No
response

Response

- Reevaluate
- Attend to patient safety
- Consider capacity to make decisions
- Maintain communication with team for chronic psychotic disorder/psychiatric service
- Consider alternate level of care

Follow-up and
communication
with primary
oncology team
and family/
caregivers

[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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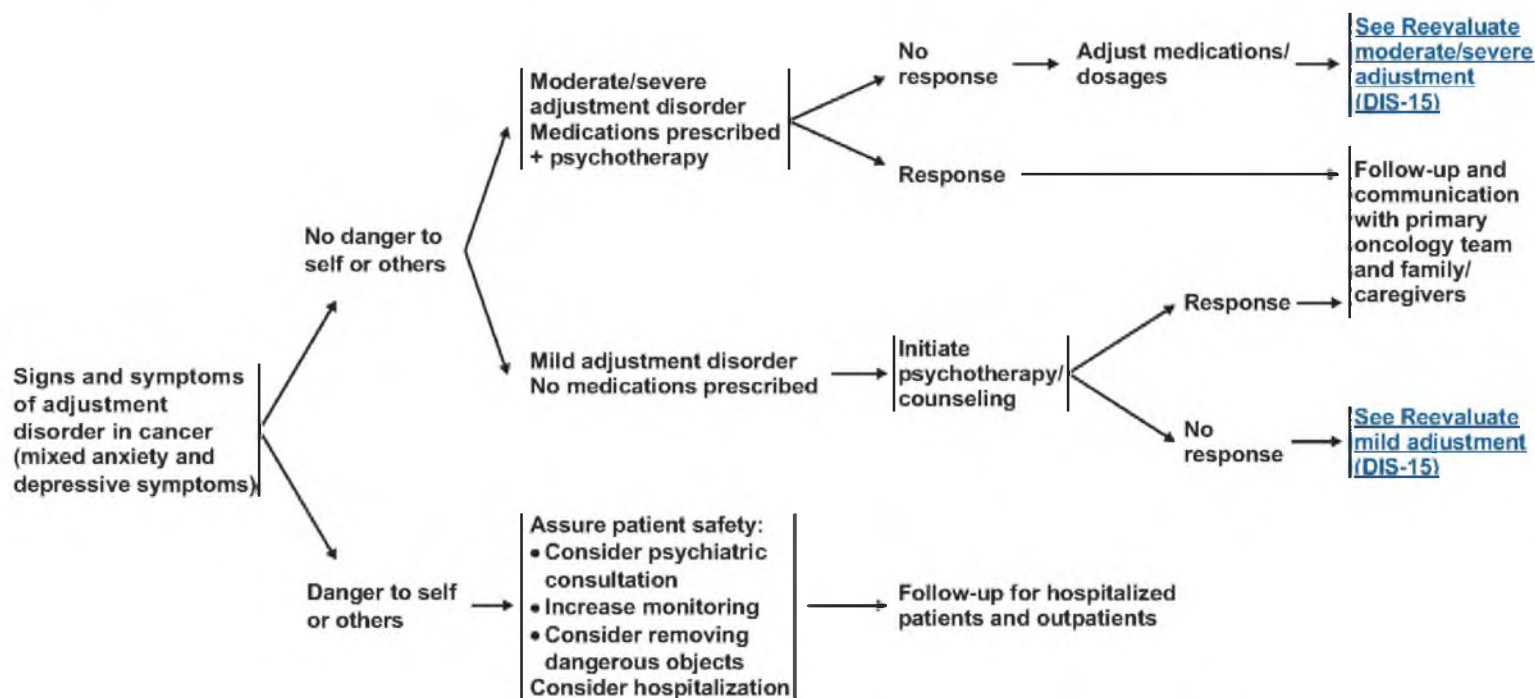
[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

**ADJUSTMENT
DISORDER**
(ICD-10 code: F43.2)

EVALUATION

TREATMENT

FOLLOW-UP



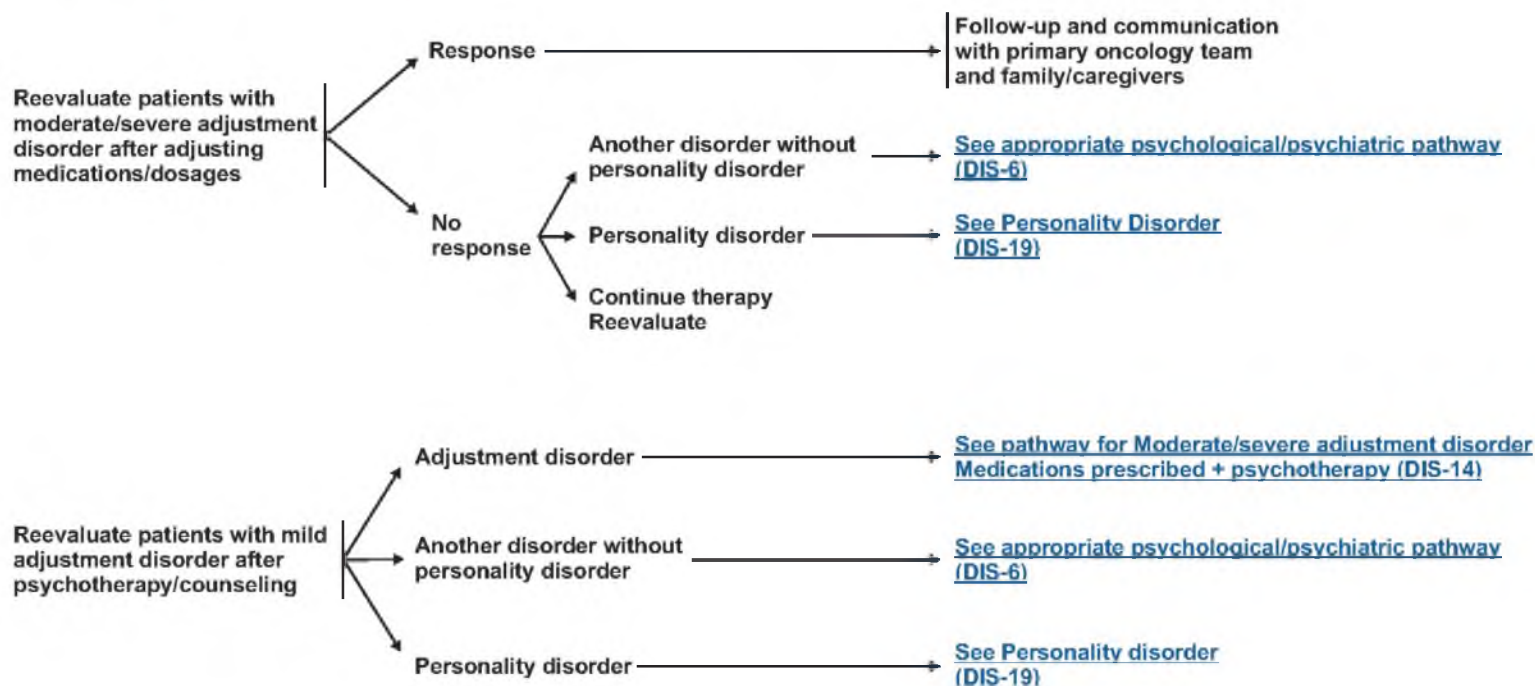
[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

ADJUSTMENT DISORDER (continued)
(ICD-10 code: F43.2)

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

ANXIETY DISORDER (ICD-10 codes: F40, F41)

EVALUATION

TREATMENT

FOLLOW-UP

Signs and symptoms of anxiety disorder in cancer:

- Anxiety due to general medical condition
- Generalized anxiety disorder
- Panic disorder
- Post-traumatic stress disorder
- Phobic disorder
- Conditioned nausea/vomiting ([See NCCN Guidelines for Antiemesis](#))
- Obsessive-compulsive disorder

Evaluation, diagnostic studies, and modification of factors related to:

- Cancer
- Treatment
- Nausea/vomiting
- Medications
- Medical causes
- Withdrawal states
- Pain
- Poor concentration
- Insomnia
- Anxiety or panic attacks
- Hypervigilance
- Fears
- Irritability
- Assess safety
- Assess decision-making capacity

Psychotherapy
± anxiolytic
± antidepressant
(category 1)

No response

Reevaluate medication
(consider neuroleptics),
psychotherapy,
support, education

Response

No response

Evaluate for depression
and other psychiatric
comorbidity

Response

Follow-up and communication
with primary oncology team
and family/
caregivers

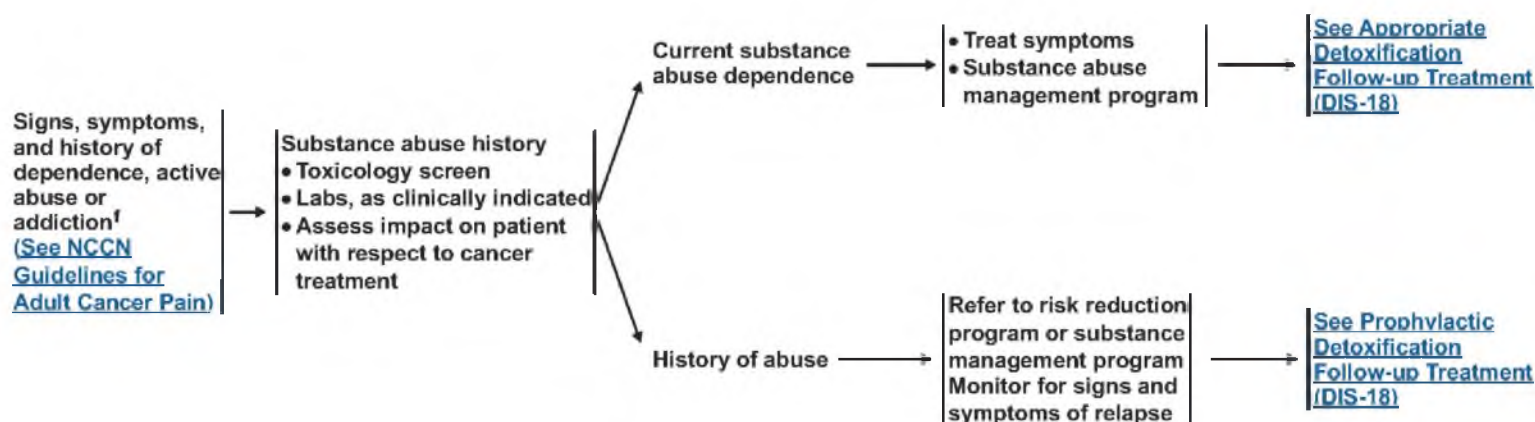
[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

SUBSTANCE-RELATED EVALUATION
DISORDER/ABUSE
(ICD-10 codes: F09-F19)

TREATMENT



^fOpioids, alcohol, tobacco, or other.

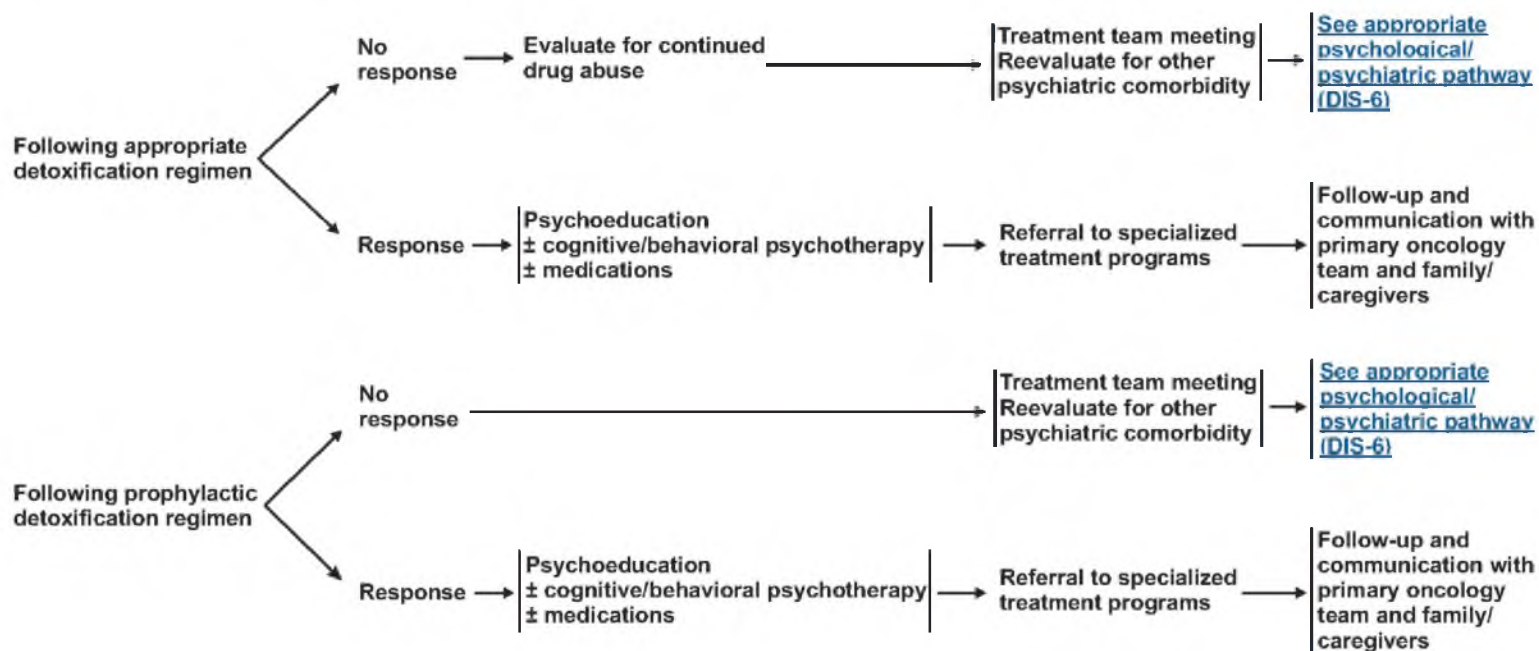
[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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SUBSTANCE-RELATED DISORDER/ABUSE (continued)
(ICD-10 codes: F09-F19)

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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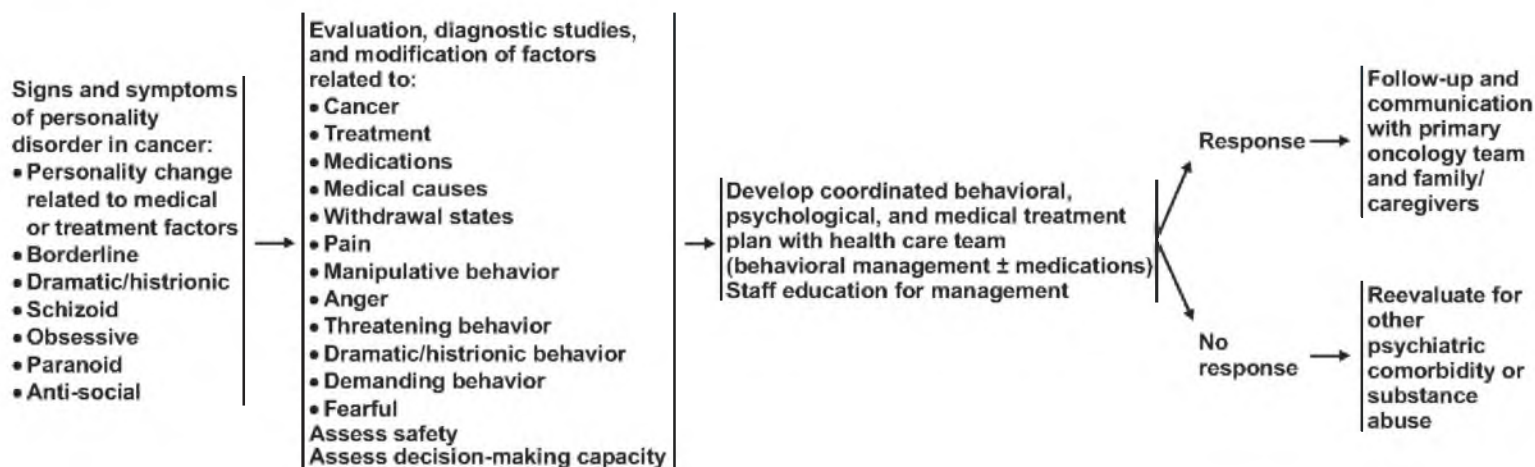
[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

PERSONALITY DISORDER (ICD-10 code: F60)

EVALUATION

TREATMENT

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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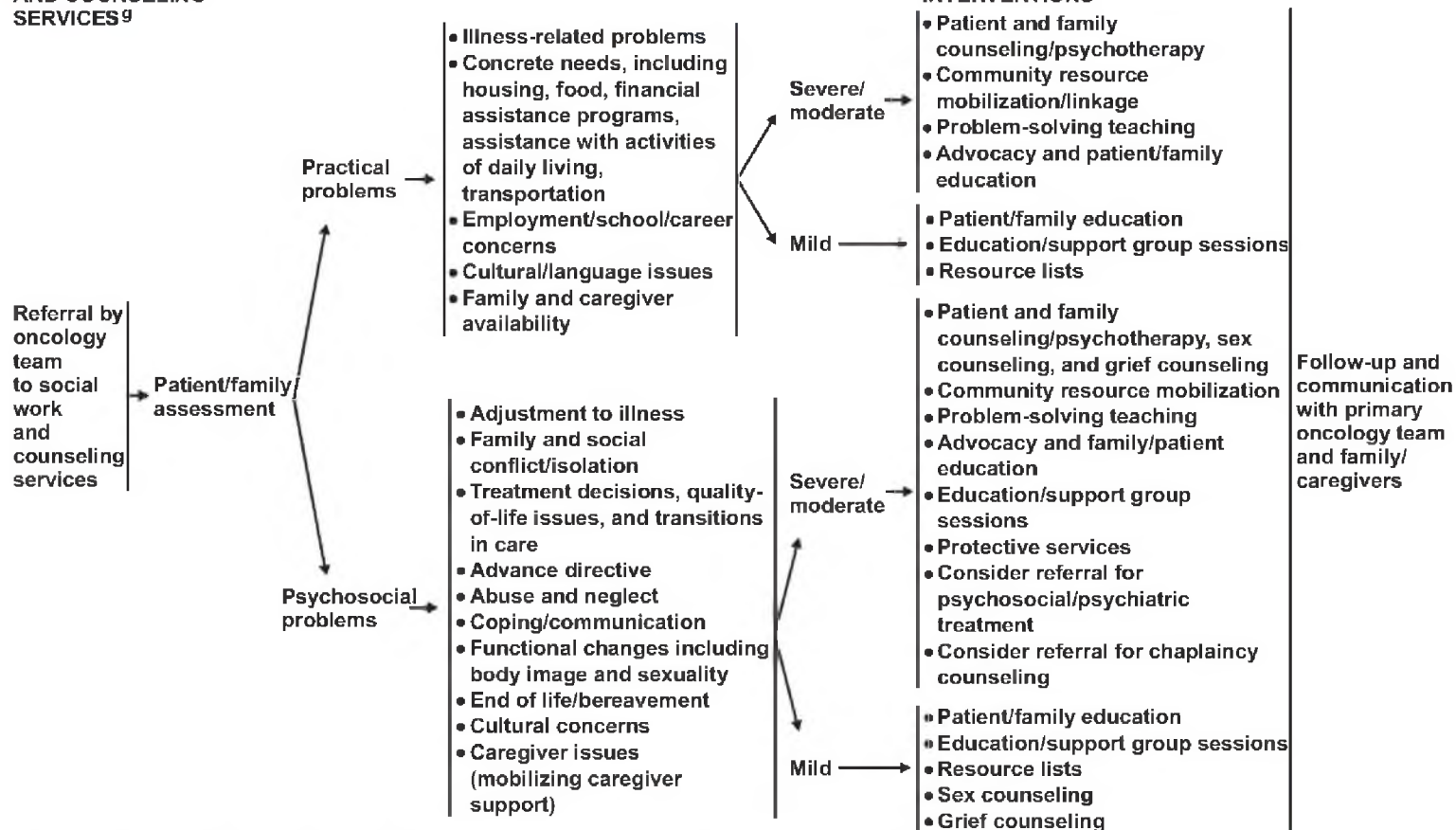
[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

SOCIAL WORK AND COUNSELING SERVICES⁹

CATEGORY

TYPE OF PROBLEM

SOCIAL WORK AND COUNSELING INTERVENTIONS



⁹Social work and counseling services include mental health services using psychological/psychiatric treatment guidelines.

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Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

[See NCCN Guidelines
for Palliative Care](#)



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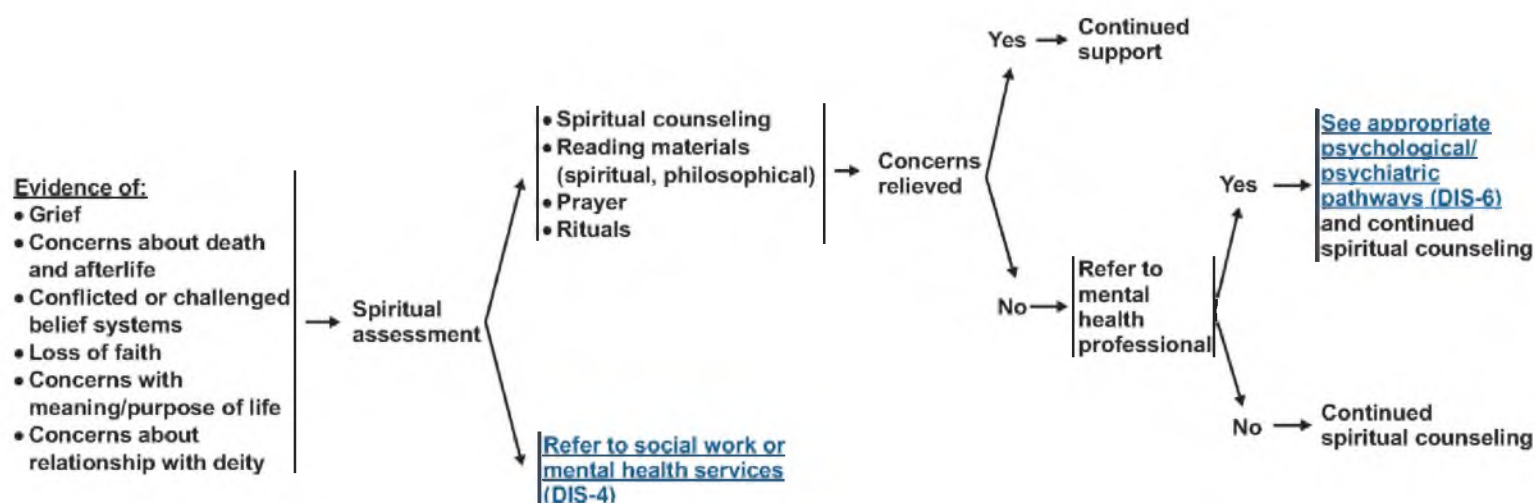
[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

CHAPLAINCY SERVICES



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CHAPLAINCY SERVICES



[Return to Chaplaincy Services \(DIS-21\)](#) [See NCCN Palliative Care Guidelines](#)

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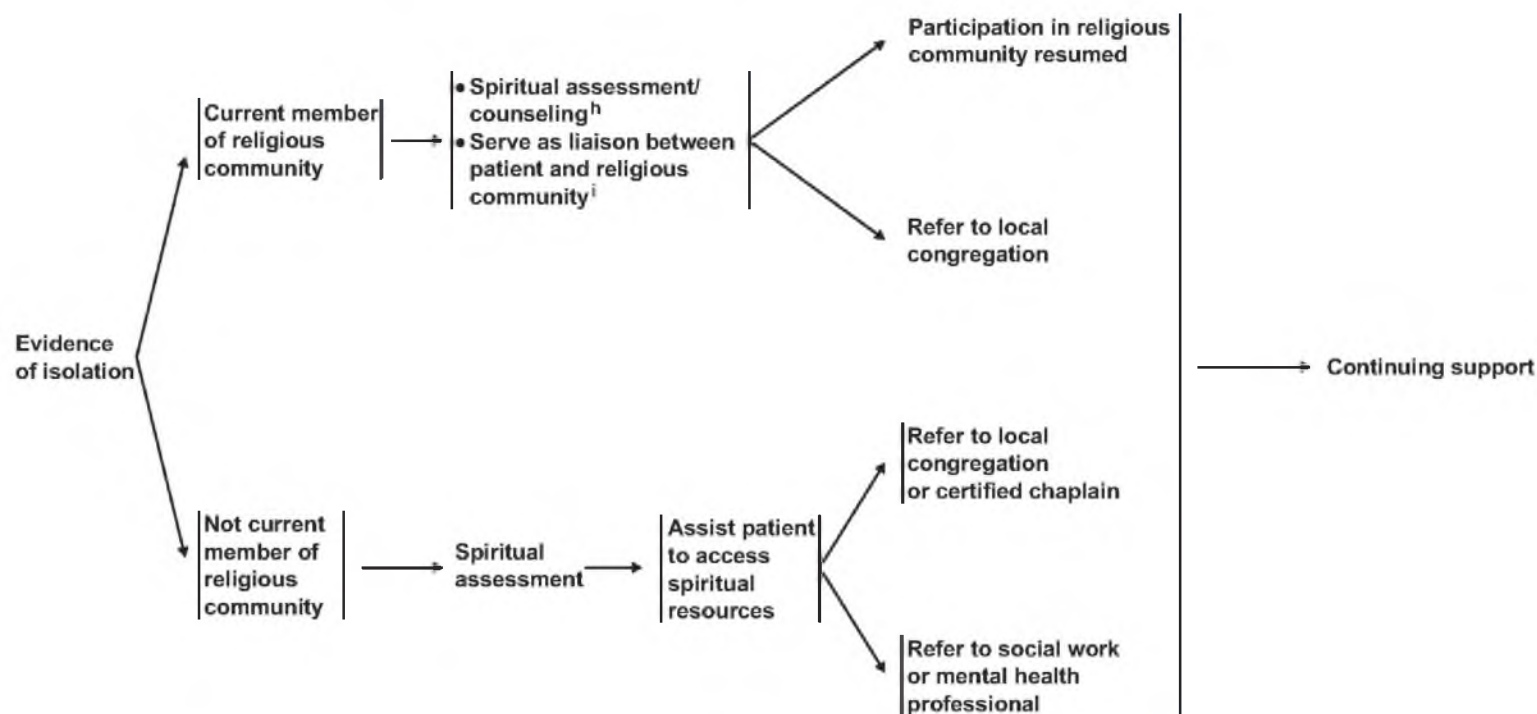


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[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

CHAPLAINCY SERVICES: ISOLATION FROM RELIGIOUS COMMUNITY



^hReferral to clergy of person's faith.

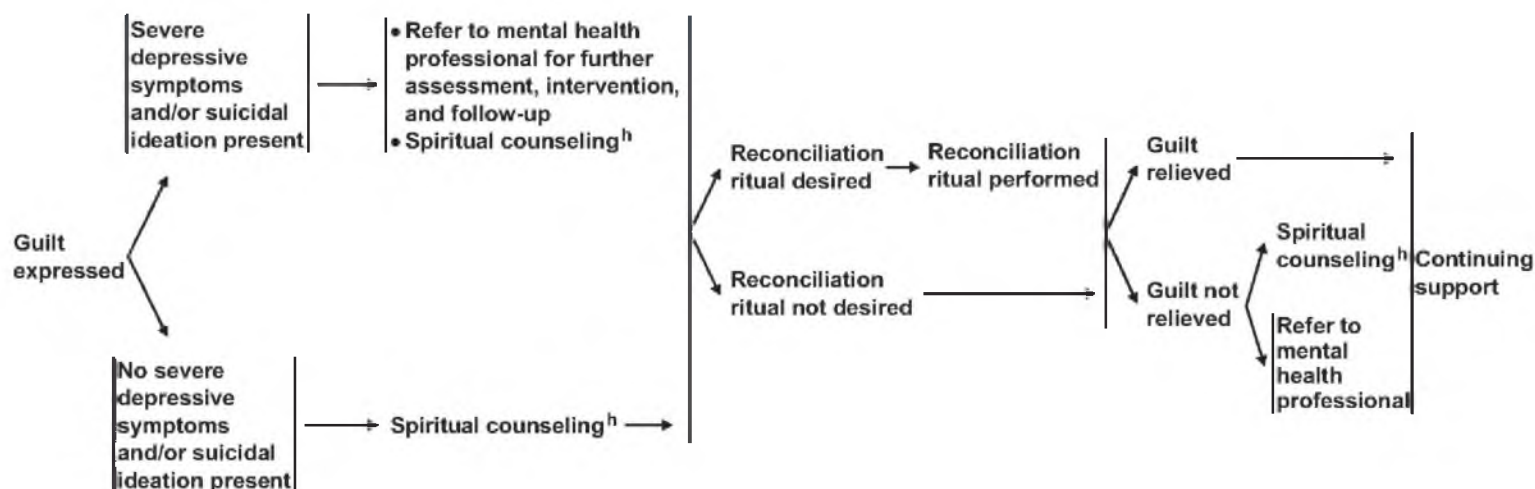
ⁱPuchalski C; Ferrell B; Birani R et al. Special Report: Improving the Quality of Spiritual Care as a dimension of Palliative Care: The Report of the Consensus Conference. Journal of Palliative Medicine 2009; 12:885-905.

[Return to Chaplaincy Services \(DIS-21\)](#)

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

CHAPLAINCY SERVICES: GUILT



^hConsider referral to community religious resource.

[Return to Chaplaincy Services \(DIS-21\)](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

CHAPLAINCY SERVICES: HOPELESSNESS



^hConsider referral to community religious resource.

[Return to Chaplaincy Services \(DIS-21\)](#)

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

**CHAPLAINCY SERVICES: CONFLICT BETWEEN RELIGIOUS BELIEFS
AND RECOMMENDED TREATMENTS**



^hConsider referral to community religious resource.

[Return to Chaplaincy Services \(DIS-21\)](#)

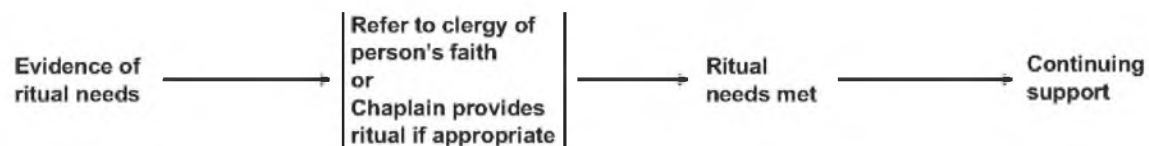
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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

CHAPLAINCY SERVICES: RITUAL NEEDS



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[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

RECOMMENDATIONS FOR IMPLEMENTATION OF STANDARDS AND GUIDELINES

- Encourage establishment of institutional interdisciplinary committees for implementation of standards and guidelines
- Conduct multicenter trials that explore brief screening instruments and pilot treatment guidelines
- Encourage institutional CQI (continuous quality improvement) projects in quality of distress management
- Develop educational approaches to distress management for staff, patients, and family

RECOMMENDED READINGS FOR IMPLEMENTATION OF PROGRAMS THAT INTEGRATE PSYCHOSOCIAL CARE INTO THE ROUTINE CARE OF PATIENTS WITH CANCER

- Bultz BD, Groff SL, Fitch M, et al. Implementing screening for distress, the 6th vital sign: a Canadian strategy for changing practice. *Psychooncology* 2011;20:463-469. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21456060>.
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Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management TOC](#)
[Discussion](#)

INSTITUTIONAL EVALUATION OF STANDARDS OF CARE¹

INTERVENTIONS

- Interdisciplinary committee tailors standards to institutional setting
- Screening tool (0-10) in clinics and inpatient setting
- Problem list
- Education of primary oncology teams via rounds and liaison with nurses and social workers
- Clarification of resources access (psychological, social, religious)
- CQI studies

→ Surveys →

OUTCOMES

Professional

Attitudes
Knowledge
Assessment

Patient

Satisfaction
(CQI survey
of impact)

¹Based on implementation/evaluation of pain management guidelines.

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

Discussion

NCCN Categories of Evidence and Consensus

Category 1: Based upon high-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

Category 2A: Based upon lower-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

Category 2B: Based upon lower-level evidence, there is NCCN consensus that the intervention is appropriate.

Category 3: Based upon any level of evidence, there is major NCCN disagreement that the intervention is appropriate.

All recommendations are category 2A unless otherwise noted.

Table of Contents

| | |
|---|------|
| Overview..... | MS-2 |
| Psychosocial Problems in Patients with Cancer..... | MS-2 |
| Barriers to Distress Management in Cancer..... | MS-3 |
| NCCN Guidelines® for Distress Management..... | MS-3 |
| The New Standard of Care for Distress Management in Cancer..... | MS-4 |
| Recommendations for Implementation of Standards and Guidelines..... | MS-5 |
| Screening Tools for Distress and Meeting Psychosocial Needs..... | MS-6 |

| | |
|-------------------------------------|------|
| The Distress Thermometer (DT) | MS-7 |
|-------------------------------------|------|

| | |
|-----------------------|------|
| The Problem List..... | MS-8 |
|-----------------------|------|

| | |
|---|------|
| Initial Evaluation and Treatment by Oncology Team | MS-9 |
|---|------|

| | |
|---|-------|
| Psychological/Psychiatric Treatment by Mental Health Professionals..... | MS-10 |
|---|-------|

| | |
|----------------------------------|-------|
| Psychosocial Interventions | MS-10 |
|----------------------------------|-------|

| | |
|----------------------------------|-------|
| Pharmacologic Interventions..... | MS-11 |
|----------------------------------|-------|

| | |
|--|-------|
| Psychological/Psychiatric Treatment Guidelines | MS-12 |
|--|-------|

| | |
|-----------------------------|-------|
| Dementia and Delirium | MS-12 |
|-----------------------------|-------|

| | |
|-------------------------------------|-------|
| Mood and Adjustment Disorders | MS-13 |
|-------------------------------------|-------|

| | |
|------------------------|-------|
| Anxiety Disorder | MS-13 |
|------------------------|-------|

| | |
|--|-------|
| Substance-Related Disorder/Abuse | MS-14 |
|--|-------|

| | |
|----------------------------|-------|
| Personality Disorder | MS-14 |
|----------------------------|-------|

| | |
|---|-------|
| Psychotic Disorder and Schizophrenia..... | MS-14 |
|---|-------|

| | |
|--|-------|
| Social Work and Counseling Services..... | MS-14 |
|--|-------|

| | |
|--|-------|
| Spiritual Care and Chaplaincy Services | MS-15 |
|--|-------|

| | |
|-------------------------|-------|
| Oncologist Burnout..... | MS-16 |
|-------------------------|-------|

| | |
|--|-------|
| The <i>Journal of Clinical Oncology</i> Special Series on Psychosocial Care in Cancer..... | MS-16 |
|--|-------|

| | |
|--------------|-------|
| Summary..... | MS-17 |
|--------------|-------|

| | |
|-----------------|-------|
| References..... | MS-18 |
|-----------------|-------|



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

Overview

In the United States, it is estimated that a total of 1,638,910 new cancer cases and 577,190 deaths from cancer will occur in 2012.¹ All patients experience some level of distress associated with the diagnosis of cancer and the effects of the disease and its treatment regardless of the stage of disease. Distress can result from the reaction to the diagnosis of cancer and to the various transitions throughout the trajectory of the disease including during survivorship. Clinically significant levels of distress occur in a subset of patients, and identification and treatment of distress are of the utmost importance.

These NCCN Distress Management guidelines discuss the identification and treatment of psychosocial problems in patients with cancer. They are intended to assist oncology teams identify patients who require referral to psychosocial resources and to give oncology teams guidance on interventions for patients with mild distress. These guidelines also provide guidance for social workers, certified chaplains, and mental health professionals that describe treatments and interventions for various psychosocial problems as they relate to patients with cancer.

Psychosocial Problems in Patients with Cancer

In the past two decades, dramatic advances in early detection and treatment options have increased the overall survival rates in patients of all ages with cancer. At the same time, these improved treatment options are also associated with substantial long-term side effects: fatigue, pain, anxiety, and depression are the most frequently reported cancer-related symptoms that interfere with the patient's ability to perform daily activities.² In addition, the physiologic effects of cancer itself and certain anti-cancer drugs can also be non-psychological contributors to distress symptoms.³⁻⁶ Furthermore, cancer patients may

have pre-existing psychological or psychiatric conditions that impact their ability to cope with cancer.

The prevalence of psychological distress in individuals varies by the type and stage of cancer as well as by patient age. In a study of 4496 cancer patients, Zabora and colleagues reported that the overall prevalence of distress was 35.1%, which varied from 29.6% for patients with gynecological cancers to 43.4% for patients with lung cancer.⁷ The prevalence of distress, depression, and psychiatric disorders has been studied in many sites and stages of cancer.⁸⁻¹⁴ Overall, surveys have found that 20-47% of newly diagnosed and recurrent cancer patients show a significant level of distress. A recent metaanalysis reported that 30-40% of patients with various types of cancer have some combination of mood disorders.¹⁵

Patients at increased risk for moderate or severe distress are those with a history of psychiatric disorder, depression, or substance abuse and those with cognitive impairment, severe comorbid illnesses, uncontrolled symptoms, communication barriers, or social issues. Social issues/risk factors include younger age; female; living alone, having young children, and prior physical or sexual abuse.

Distress is a risk factor for non-adherence to treatment, especially with oral medications. In women with primary breast cancer, Partridge and colleagues observed that the overall adherence to tamoxifen decreased to 50% in the fourth year of therapy and nearly one fourth of patients may be at risk of inadequate clinical response due to poor adherence.¹⁶ In a meta-analysis, DiMatteo and colleagues found that noncompliance was 3 times greater in depressed patients as compared to non-depressed patients.¹⁷ In addition to decreased adherence to treatment, failure to recognize and treat distress leads to several problems: patients may have trouble making decisions about treatment and they



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

may make extra visits to the physician's office and emergency room, which takes more time and causes greater stress for the oncology team.^{18,19} Distress in patients with cancer also leads to poorer quality of life and can even negatively impact survival.^{14,20,21} Furthermore, cancer survivors with untreated distress have poorer compliance with surveillance screenings and are less likely to exercise and quit smoking.²²

Early evaluation and screening for distress leads to early and timely management of psychological distress, which in turn improves medical management.^{23,24} A recent randomized study showed that routine screening for distress, with referral to psychosocial resources as needed, led to lower levels of distress at 3 month than did screening without personalized triage for referrals.²⁵ Those with the highest level of initial distress benefitted the most. In addition, there is evidence from randomized trials that psychologically effective interventions may lead to a survival advantage in patients with cancer.²⁶ Overall, early detection and treatment of distress leads to

- better adherence to treatment
- better communication
- fewer calls and visits to the oncologist's office
- avoidance of patients' anger and development of severe anxiety or depression

Barriers to Distress Management in Cancer

Less than half of distressed patients with cancer are actually identified and referred for psychosocial help.^{27,28} Many patients with cancer who are in need of psychosocial care are not able to get the help they need due to the under-recognition of patient's psychological needs by the primary oncology team and lack of knowledge of community resources.²⁹ The need is particularly acute in community oncologists'

practices where there are few to no psychosocial resources, and cancer care is often provided by short visits.

An additional barrier to patients receiving the psychosocial care they require is the stigma associated with psychological problems. For many centuries, patients were not told their diagnosis of cancer due to the stigma attached to the disease. Since the 1970s, this situation has changed and patients are well aware of their diagnosis and treatment options.³⁰ However, patients are reluctant to reveal emotional problems to the oncologist. The words "psychological," "psychiatric," and "emotional" are as stigmatizing as the word "cancer." The word "distress" is less stigmatizing and more acceptable to patients and oncologists than these terms, but psychological issues remain stigmatized even in the context of coping with cancer. Consequently, patients often do not tell their physicians about their distress and physicians do not inquire about the psychological concerns of their patients. The recognition of patients' distress has become more difficult as cancer care has shifted to the ambulatory setting, where visits are often short and rushed. These barriers prevent distress from receiving the attention it deserves, despite the fact that this is a critical component of the total care of the person with cancer.

NCCN Guidelines® for Distress Management

A major milestone in the improvement of psychosocial care in oncology was made by the NCCN when it established a panel to develop clinical practice guidelines, using the NCCN format. The panel began to meet in 1997 as an interdisciplinary group. The clinical disciplines involved were: oncology, nursing, social work and counseling, psychiatry, psychology, and clergy. A patient advocate was also on the panel. Traditionally, clergy have not been included on NCCN guideline panels,



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

but the NCCN recognized that many distressed patients prefer a certified chaplain.³¹

The first step was to understand why this area has been so difficult to develop. The panel members decided that words like "psychiatric" or "psychological" are stigmatizing; patients and oncologists are reluctant to label any symptoms or patients as such. The way around this barrier was developed by using a term that would feel "normal" and non-stigmatizing. This led to the first published guidelines in 1999 for the management of *distress* in cancer patients. This accomplishment provided a benchmark, which has been used as the framework in the handbook for oncology clinicians published by the IPOS press (The International Psycho-Oncology Society).³²

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

Recommendations in the guidelines are based on evidence and on consensus among panel members. In addition to the guidelines for oncologists, the panel established guidelines for social workers, certified chaplains, and mental health professionals (psychologists, psychiatrists, psychiatric social workers, and psychiatric nurses).³³

The New Standard of Care for Distress Management in Cancer

Psychosocial care had not been considered as an aspect of quality cancer care until a 2007 Institute of Medicine (IOM) report, *Cancer Care for the Whole Patient*.³⁴ The IOM report is based on the pioneering work of the NCCN panel, which recommends screening for distress and the development of a treatment plan with referrals as needed to psychosocial resources.³³ Psychosocial care is now a part of the new standard for quality cancer care and should be integrated into routine care.^{34,35} The IOM report supported the work of the NCCN Guidelines for Distress Management by proposing a model for the effective delivery of psychosocial health services that could be implemented in any community oncology practice:

- Screening for distress and psychosocial needs
- Making a treatment plan to address these needs and implementing it
- Referring to services as needed for psychosocial care
- Reevaluating, with plan adjustment as appropriate.

In Canada, routine psychosocial care is part of the standard of care for patients with cancer; emotional distress is considered the sixth vital sign that is checked routinely along with pulse, respiration, blood pressure, temperature, and pain.^{18,36}

In August 2012, the Commission on Cancer (CoC) of the American College of Surgeons (ACS) released new accreditation standards for hospital cancer programs (<http://www.facs.org/cancer/coc/programstandards2012.html>). Their patient-centered focus now includes screening all patients with cancer for psychosocial distress.

The standards of care for managing distress proposed by the NCCN Distress Management panel are broad in nature and should be tailored



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

to the particular needs of each institution and group of patients. The overriding goal of these standards is to ensure that no patient with distress goes unrecognized and untreated. The panel based these standards of care on quality improvement guidelines for the treatment of pain.³⁷ The standards of care developed by the NCCN Distress Management panel, which can also be found in the guidelines, are:

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.
- Screening should identify the level and nature of the distress.
- All patients should be screened to ascertain their levels of distress at the initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status (remission, recurrence, or progression).
- Distress should be assessed and managed according to clinical practice guidelines.
- Interdisciplinary institutional committees should be formed to implement standards for distress management.
- Educational and training programs should be developed to ensure that health care professionals and certified chaplains have knowledge and skills in the assessment and management of distress.
- Licensed mental health professionals and certified chaplains experienced in the psychosocial aspects of cancer should be readily available as staff members or by referral.
- Medical care contracts should include reimbursement for services provided by mental health professionals.
- Clinical health outcomes measurements should include assessment of the psychosocial domain (eg, quality of life and patient and family satisfaction).
- Patients, families, and treatment teams should be informed that management of distress is an integral part of total medical care and

provided with appropriate information about psychosocial services in the treatment center and in the community.

- Finally, the quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.

Patients and families should be made aware that this new standard exists and that they should expect it in their oncologist's practice. The Alliance (<http://www.wholecancerpatient.org/>) is a coalition of professional and advocacy organizations whose goal is to advance the recommendations from the IOM report. Their website has hundreds of psychosocial resources for health care professionals, patients, and caregivers, searchable by state.

Recommendations for Implementation of Standards and Guidelines

Jacobsen and colleagues conducted a study in 2005 evaluating the implementation of NCCN Guidelines for Distress Management by 15 NCCN member institutions.³⁸ Eight institutions (53%) conducted routine distress screening of some patient populations and an additional 4 institutions (27%) also preformed pilot testing of screening strategies. However, concordance to NCCN Guidelines (screening all patients) was observed in only 20% of the member institutions at that time.

Implementation of the IOM standards for integration of psychosocial care into the routine care of patients with cancer can be improved by providing feedback to oncology practices on the quality of their psychosocial care. Quality indicators were thus developed by Jacobsen and colleagues. They developed a patient chart audit which permits an oncologists' office or clinic to evaluate the quality of their psychosocial care.³⁹ The survey queries whether there is documentation that the patient's current emotional well-being was assessed and if there is



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

documentation that any action was taken if the patient was identified as having a problem. These quality indicators can be used widely to determine the quality of psychosocial care given by a clinic or office.

The Quality Oncology Practice Initiative (QOPI) was started in 2002 by the American Society of Clinical Oncology (ASCO) as a pilot project (<http://qopi.asco.org/program.html>).⁴⁰ This program became available to all ASCO member medical oncologists in 2006. Jacobson's psychosocial quality indicators were added as part of the core measures in the QOPI quality measures in 2008,⁴¹ in a recent analysis, Jacobson and colleagues reported that practices participating in QOPI demonstrated improved performance, with initially low-performing practices showing the greatest improvement.⁴¹ Blayney and colleagues from the University of Michigan Comprehensive Cancer Center recently reported that QOPI can be adapted for use in practice improvement at an academic medical center.⁴² The American Psychosocial Oncology Society (APOS) has also adopted these quality indicators.⁴³

The panel encourages the establishment of institutional interdisciplinary committees to implement and monitor distress management. The interdisciplinary committee should be responsible for evaluation of standard care in distress management with continuous quality improvement (CQI) studies. The panel encourages interdisciplinary CQI studies to assess the quality of distress management programs as well as the efficacy of standards of care and implementation of these NCCN Guidelines for Distress Management and the new quality standard established by the IOM report.³⁴ The new CoC accreditation standards for hospital cancer programs include screening all patients with cancer for psychosocial distress, so psychosocial care is now on all institutions' report cards.

Multicenter randomized trials and pilot testing are needed to compare the efficacy of brief screening instruments. Educational approaches should be developed for medical staff, patients, and caregivers to increase their awareness of the prevalence of distress and of psychological interventions.

The MD Anderson Cancer Center published a report on their efforts to implement the integration of psychosocial care into clinical care.⁴⁴ The authors outline strategies they used to accomplish the required cultural shift and describe the results of their efforts. Other groups have also described their efforts towards implementing psychosocial screening in various outpatient settings.⁴⁵⁻⁴⁹ Additional guidance for the implementation of the new IOM standards has been published.⁵⁰⁻⁵² In Canada, a national approach has been used to implement screening for distress. Their strategies have been described.⁵³ Groups in Italy and France have also described results of their preliminary efforts toward the implementation of psychosocial distress screening.^{54,55} A reading list for implementation of programs that integrate psychosocial care into the routine care of patients with cancer is provided in these guidelines.

Overall, to implement the new standard of integrating psychosocial care into the routine care of all patients with cancer, it is critical to have a fast and simple screening method that can be used to identify patients who require psychosocial care and/or referral to psychosocial resources.⁵² The NCCN Distress Management panel developed such a rapid screening tool, as discussed below.

Screening Tools for Distress and Meeting Psychosocial Needs

Identification of a patient's psychological needs is essential to develop a plan to manage those needs. Ideally, patients tell their oncologists about their problems or they respond to the oncologist's query about



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

them. In routine clinical practice, time constraints and the stigma related to psychiatric and psychological needs often leads to no discussion of these issues. Screening tools have been found to be effective and feasible in reliably identifying distress and the psychosocial needs of patients.⁵⁶⁻⁵⁸ Mitchell and colleagues recently reported that ultra-short methods (PHQ2 or the Distress Thermometer) were acceptable to about three quarters of clinicians.^{59,60} Automated touch-screen technologies have also been used for psychosocial screening of patients with cancer.^{61,62} Recently, an internet-based program that includes distress screening, reporting, referrals, and followup components has been developed. The screening component was validated in a trial of 319 community-based cancer survivors and showed good psychometric properties.⁶³

A recent metaanalysis compared 8 tools designed to screen for depression in the cancer setting that had been validated by at least 2 separate studies.⁶⁴ This analysis included the Hospital Anxiety and Depression Scale (HADS), the Beck Depression Inventory version 2 (BDI-II), and the Distress Thermometer (DT, discussed below).

The Distress Thermometer (DT)

The NCCN Distress Management panel developed the distress thermometer (DT), a now well known tool for initial screening, which is similar to the successful rating scale used to measure pain: 0 (no distress) to 10 (extreme distress). The DT serves as a rough initial single-item question screen, which identifies distress coming from any source, even if unrelated to cancer. The receptionist gives it to the patient in the waiting room.

The word "distress" was chosen as described above, because it is less stigmatizing and more acceptable to patients and oncologists than other terms such as psychiatric, psychosocial, or emotional. Using this

non-stigmatizing word diminishes clinicians' concerns that the patient will be embarrassed or offended by these questions. Asking an objective question such as, "How is your pain today on a scale of 0 to 10?" made it easier and more comfortable for caregivers to learn about patients' pain. Similarly, asking patients, "How is your distress today on a scale of 0 to 10?" opens a dialogue with the oncologist or nurse for a discussion of emotions that is more acceptable.

The patient in the waiting room places a mark on the DT scale answering: "How distressed have you been during the past week on a scale of 0 to 10?" Scores of 4 or higher suggest a level of distress that has clinical significance. If the patient's distress level is mild (score is less than 4 on the DT), the primary oncology team may choose to manage the concerns by usual clinical supportive care management. If the patient's distress level is 4 or higher, the nurse looks at the problem list (see below) to identify key issues of concern and asks further questions to determine to which resources (mental health, social work and counseling, or chaplaincy services) the patient should be referred.

The DT has been validated by several studies in patients with different types of cancer and has revealed concordance with the Hospital Anxiety and Distress Scale (HADS).^{56,65-71} The DT has shown good sensitivity and specificity. The needs assessment surveys performed in ambulatory clinics using these screens show 20-40% of patients have significant levels of distress. Two studies validated a version of the DT with an expanded problems list.^{72,73} Tuinman and colleagues validated the DT with the 46-item problem list in a cross-sectional group of 227 cancer patients.⁷³ Graves and colleagues validated the DT with an adapted problems list with two new problem categories (information concerns and cognitive problems) in lung cancer patients.⁷² The DT is also a useful tool for screening distress among bone marrow transplant patients.^{74,75} The DT had acceptable overall accuracy and greater



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

sensitivity and specificity when compared to the Center for Epidemiological Studies-Depression Scale (CES-D) in the assessment of depression in patients undergoing bone marrow transplants.⁷⁴

The Problem List

The screening tool developed by the NCCN Distress Management panel includes a 39-item Problem List, which is on the same page with the DT. The Problem List asks patients to identify their problems in five different categories: practical, family, emotional, spiritual/religious, and physical (see Screening Tools for Measuring Distress in the guidelines). The completed list is reviewed by the nurse, because he/she is present at all visits and is the likely person to ask clarifying questions. Social workers are often not immediately available in busy clinics.

Cognitive Impairment

"Memory/concentration problems" is one item on the Problem List. Cognitive impairment is common in patients with primary central nervous system (CNS) cancers, due to both the effects of brain tumors themselves and the effects of treatment targeted to the brain.^{76,77} Recent evidence has shown that chemotherapy-related cognitive dysfunction is also prevalent in patients with non-CNS cancers and without brain metastases.⁷⁸⁻⁸¹ Chemotherapy can cause subtle cognitive changes, studied primarily in breast and lymphoma patients. It can continue over years and at times, when more severe, can impact quality of life and function. The underlying mechanisms for chemotherapy-induced cognitive changes are not known. Recent studies have reported elevated levels of cytokines or DNA damage as some of the possible mechanisms.⁸² In addition, evidence suggests that cancer itself and therapies other than chemotherapy, such as hormone therapy, can cause cognitive impairments in patients with cancer.⁸³⁻⁸⁶ A recent national cross-sectional study found that a history of cancer is independently associated with a 40% increase in the likelihood of self-

reported memory problems.⁸⁷ A better understanding of the mechanisms that cause cancer-related cognitive impairment is essential for the development of treatments to improve cognitive function and quality of life in patients with cancer.^{76,77,88}

There is no standard treatment for the management of cognitive changes in patients with cancer. Cognitive behavior therapy, cognitive rehabilitation programs, and exercise may be effective interventions to improve cognitive function in patients with cancer.^{89,90} In addition, some studies have shown that the use of psychostimulants such as methylphenidate and modafinil improved cognitive function in patients with cancer.⁹¹⁻⁹³ Donepezil, a reversible acetylcholinesterase inhibitor (approved to treat mild to moderate dementia in patients with Alzheimer's disease) also improved cognitive function, mood, and health-related quality of life in patients with primary low-grade glioma.⁹⁴ Further placebo controlled trials are needed to confirm these preliminary findings.

In October 2006 the International Cognition and Cancer Task Force (ICCTF), comprised of a multidisciplinary group of health professionals and health advocates, was formed. The mission of ICCTF is to advance understanding of the impact of treatment-related cognitive and behavioral functioning in patients with non-CNS cancers.⁹⁵ ICCTF also has a web site (www.icctf.com) to provide up-to-date information to both physicians and patients seeking assistance in the management of cognitive symptoms associated with cancer treatment.

Fertility

Another item on the Problem List is the "ability to have children." Chemotherapy and radiation therapy also have an impact on the fertility of patients, especially in those who are of child-bearing age.⁹⁶ Therefore, the panel has included "ability to have children" as one of



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

the items under the family problems category. MyOncofertility.org is a useful patient education resource for those who are concerned about the possible effect of cancer treatment on their fertility.

Substance Abuse

For the 2013 version of these guidelines, the panel added substance abuse to the list of possible physical problems. Substance abuse in patients with cancer who do not have a history of abuse or addiction is rare and is usually caused by insufficient symptom control. Improving symptom control often alleviates the substance dependence. This problem is discussed in more detail below in Substance-Related Disorder/Abuse.

Initial Evaluation and Treatment by Oncology Team

The panel recommends that all patients be assessed in the waiting room using a simple screening tool. While there are several types of screening tools, the DT and the accompanying Problem List are recommended to assess the level of distress and to identify causes of distress. If the patient's distress is moderate or severe (thermometer score of 4 or more), the oncology team must recognize that score as a trigger to a second level of questions should prompt referral to a mental health professional, social worker, or spiritual counselor, depending on the problems identified in the Problem List. Common symptoms that require further evaluation are: excessive worries and fears, excessive sadness, unclear thinking, despair and hopelessness, severe family problems, social problems, and spiritual or religious concerns.

Mild distress (DT score of less than 4) is routinely managed by the primary oncology team and represents what the panel terms "expected distress" symptoms. The symptoms that the team manages are fear, worry, and uncertainty about the future; concerns about the illness; sadness about loss of good health; anger and the feeling that life is out

of control; poor sleep, poor appetite, and poor concentration; preoccupation with thoughts of illness, death, treatment, and side effects; and concerns about social roles (eg, as mother, father). Most patients experience these symptoms at the time of diagnosis and during arduous treatment cycles. They might persist long after the completion of treatment. For instance, minor symptoms are often misinterpreted by survivors as a sign of recurrence, which causes fear and anxiety until they are reassured.

The primary oncology team is the first to deal with these painful problems. The oncologist, nurse, and social worker each have a critical role. First and foremost is the quality of the physician's communication with the patient, which should occur in the context of a mutually respectful relationship so that the patient can learn the diagnosis as well as understand the treatment options and side effects.^{97,98} Adequate time should be provided for the patient to ask questions and for the physician to put the patient at ease. When communication is done well at diagnosis, the stage is set for future positive trusting encounters. It is important to ensure that the patient mentally grasps what has been said. Information may be reinforced with drawings or by taping the session and giving the tape to the patient. Communication skills training for oncology professionals who teach, for example, how to discuss prognosis and unanticipated adverse events and how to reach a shared treatment decision may be very helpful. Communication skills training was recently reviewed by Kissane et al.⁹⁹

It is important for the oncology team to acknowledge that this is a difficult experience for the patient and that distress is normal and expected. Being able to express distress to the staff helps provide relief to the patient and builds trust. The team needs to ensure that social supports are in place for the patient and that he or she knows about community resources such as support groups, teleconferences, and



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

help lines. The IOM report contains a list of national organizations and their toll-free numbers.³⁴ Some selected organizations that provide free information services to cancer patients are:

- American Cancer Society (www.cancer.org)
- American Institute for Cancer Research (www.aicr.org)
- American Psychosocial Oncology Society (www.apos-society.org)
(APOS provides a toll-free Help Line [1-866-276-7443] to which patients and their caregivers can be referred to help them find psychological resources in their community.)
- CancerCare (www.cancercare.org)
- National Cancer Institute (www.cancer.gov)
- Cancer.net, sponsored by ASCO (www.cancer.net).
- Cancer Support Community
(<http://www.cancersupportcommunity.org>)

Clinicians should be aware of the evidence-supported interventions available for the management of distress. In addition to these NCCN Guidelines for Distress Management (www.nccn.org), the following clinical practice guidelines will be useful to clinicians, including the oncology team:

- Clinical practice guidelines for the psychosocial care of adults with cancer have been developed by the Australian National Breast Cancer Centre and the National Cancer Control Initiative (<http://www.nhmrc.gov.au/guidelines/publications/cp90>).
- National Cancer Institute and several partners have developed a web site that provides information about research-tested intervention programs (<http://rtips.cancer.gov/rtips/index.do>).

Follow-up at regular intervals or at transition points in illness is an essential part of the NCCN Guidelines for Distress Management and the IOM model for care of the whole patient. This reassessment is particularly important in elderly cancer patients.¹⁰⁰

Psychological/Psychiatric Treatment by Mental Health Professionals

Psychosocial Interventions

Psychosocial interventions have been effective in reducing distress and improving overall quality of life among cancer patients.^{34,35} The 2007 IOM report noted that there is a strong evidence base that supports the value of psychosocial interventions in cancer care.³⁴ The review examined the range of interventions (psychological, social, and pharmacologic) and their impact on any aspect of quality of life, symptoms, or survival. The extensive review found randomized clinical trials, systematic reviews, and meta-analyses supporting the conclusion that psychosocial aspects must be integrated into routine cancer care in order to give quality cancer care. Cognitive-behavioral therapy (CBT), supportive psychotherapy, and family and couples therapy are the three key types of psychotherapies discussed in the IOM report.³⁴

Cognitive-Behavioral Therapy

CBT involves relaxation, enhancing problem-solving skills, and the identification and correction of inaccurate thoughts associated with depressed feelings. In randomized clinical trials, CBT has been shown to effectively reduce psychological symptoms (anxiety and depression)^{101,102} as well as physical symptoms (pain and fatigue)¹⁰³ in patients with cancer. A recent systematic review, however, concluded that data on the efficacy of CBT in patients with advanced cancer is lacking.¹⁰⁴



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

Ferguson and colleagues have developed a brief CBT intervention (Memory and Attention Adaptation Training [MAAT]) aimed at helping breast cancer survivors manage cognitive dysfunction associated with adjuvant chemotherapy.¹⁰⁵ In this single-arm pilot study, improvements in self reporting of cognitive function, quality of life, and standard neuropsychological test performance were observed in all patients (29 women at an average of 8 years after adjuvant chemotherapy for stage I-II breast cancer). The authors have since performed a randomized study to evaluate the efficacy of MAAT.⁸⁹ They found that patients in the intervention arm had improved verbal memory performance and spiritual well-being.

Supportive Psychotherapy

Supportive psychotherapy, aimed at flexibly meeting patients' changing needs, is most widely used. Different types of group psychotherapy have been evaluated in clinical trials among cancer patients. Supportive-expressive group therapy has been shown to improve quality of life and psychological symptoms, especially improvements in mood and pain control in patients with metastatic breast cancer.^{106,107} Cognitive-existential group therapy has been found to be useful in women with early-stage breast cancer receiving adjuvant chemotherapy.¹⁰⁸ Meaning-centered group psychotherapy, designed to help patients with advanced cancer sustain or enhance a sense of meaning, peace, and purpose in their lives (even as they approach the end of life), has also been shown to reduce psychological distress among patients with advanced cancer.^{109,110} Recently, dignity therapy has been assessed in a randomized controlled trial of patients with a terminal diagnosis (not limited to cancer).¹¹¹ Although there was no significant improvement in levels of distress in patients receiving dignity therapy as measured by several scales, significant improvements,

specifically for depression and self-reported aspects of quality-of-life, were seen.

Family and Couples Therapy

A cancer diagnosis causes distress in partners and family as well as the patient. Psychosocial interventions aimed at patients and their families together might lessen distress more effectively than individual interventions. In a longitudinal study of couples coping with early-stage breast cancer, mutual constructive communication was associated with less distress and more relationship satisfaction for both the patients and partners compared to demand/withdraw communication or mutual avoidance, suggesting that training in constructive communication would be an effective intervention.¹¹²

Family and couples therapy has not been widely studied in controlled trials. A small randomized trial was recently reported in which patients and their caregivers received 8 emotionally focused therapy sessions or standard care.¹¹³ Significant improvements in marital functioning and patient experience of empathetic care by the caregiver were seen. These effects were maintained 3 months after the intervention. In addition, a randomized controlled trial showed that family-focused grief therapy can reduce the morbid effects of grief in families with terminally ill cancer patients.¹¹⁴ A recent systematic review of 23 studies that assessed the efficacy of psychosocial interventions for couples affected by cancer found evidence that couples therapy might be at least as effective as individual therapy.¹¹⁵

Pharmacologic Interventions

Research suggests that antidepressants and anxiolytic drugs are beneficial in the treatment of depression and anxiety in adult cancer patients.¹¹⁶⁻¹²² In randomized controlled trials, alprazolam^{123,124} (a benzodiazepine) and fluoxetine^{125,126} (a selective serotonin reuptake



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

inhibitor [SSRI]) have been effective in improving depressive symptoms in cancer patients. SSRIs are widely used for depression and anxiety symptoms.

Psychostimulant drugs help in the management of fatigue.¹²⁷⁻¹²⁹

Methylphenidate is likely effective for the treatment of cancer-related fatigue, but additional trials are needed. Wakefulness-promoting agents such as modafinil are also commonly used to treat fatigue in patients with cancer, but their efficacy remains to be shown conclusively.¹²⁷

Psychological/Psychiatric Treatment Guidelines

Patients scoring 4 or higher on the DT during any visit to the oncologist are referred to the appropriate supportive service (mental health, social work and counseling, or chaplaincy services) based on the identified problem.

Mental health professionals are expected to conduct a psychological or psychiatric evaluation that includes an assessment of the nature of the distress, behavior and psychological symptoms, psychiatric history, use of medications, pain, fatigue, sleep disturbances, other physical symptoms, cognitive impairment, body image and sexuality, and capacity for decision making and physical safety. A psychiatrist, psychologist, nurse, advanced practice clinician, or social worker may perform the evaluation. All of these professionals are skilled in mental health assessment and treatment. The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) classification of mental disorders is used to identify the psychological and psychiatric disorders that commonly occur in patients with cancer.

The panel has developed evaluation and treatment guidelines for the most commonly encountered psychiatric disorders: dementia, delirium (encephalopathy), mood disorder, adjustment disorder, anxiety

disorder, substance abuse-related disorder, and personality disorder. For the 2012 guidelines, the panel developed new guidelines to address psychotic disorder and schizophrenia. Psychotropic drugs are recommended throughout the guidelines to treat psychiatric disorders. It is important to note that these drugs can sometimes interact with anticancer therapies and cause adverse effects. A recent article reviews some of these interactions and discusses other challenges in treating cancer in patients with severe mental illness.¹³⁰

Dementia and Delirium

Dementia and delirium are cognitive impairments that can severely impair the patient's decision-making capacity. Dementia is a permanent cognitive impairment. It is not a common complication of cancer treatment, but is often present in elderly patients as a comorbid condition.^{131,132} Dementia can be treated with cognitive rehabilitation, with or without medications, though treatment is largely management of behavior. Delirium is a short-term cognitive impairment. It is usually reversible and occurs in cancer treatment related to any toxic state, and it often related to medication, particularly opioids.¹³³ Delirium is managed by attention to safety, modification of opioids or other medications, neuroleptics, and family support and education.¹³⁴ The United Kingdom's National Institute for Health and Clinical Excellence (NICE) issued detailed guidelines for the diagnosis, prevention, and management of delirium.¹³⁵ In addition, a recent comprehensive review in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer by Breitbart and Alici¹³⁶ describes the evidence base for recommended pharmacologic and non-pharmacologic treatments for delirium in patients with cancer.



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

Mood and Adjustment Disorders

Mood disorders such as depression and adjustment disorder (mixed anxiety and depressive symptoms) are common in patients with cancer and can be debilitating. Patients with uncontrolled mood and adjustment disorders can develop suicidal tendencies. The incidence of suicide among cancer patients in the United States is twice that of the general population.¹³⁷⁻¹³⁹ Older patients and men with head and neck cancer or myeloma seem to have a higher risk of suicide.¹⁴⁰

Mood disorder is usually managed with psychotherapy or an antidepressant with or without anxiolytics. The evidence for these treatments has been described.^{35,141-143} In particular, a recent review by Li et al¹⁴⁴ in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer comprehensively describes the evidence for recommended pharmacologic and psychosocial interventions for treating depression in patients with cancer. Referral to social work and counseling services and chaplaincy services may also be considered. Patients considered a danger to themselves or others should be considered for psychiatric consultation. Increased monitoring is also warranted, and the removal of dangerous objects should be considered. Psychiatric treatment and hospitalization may sometimes be necessary.

Anxiety Disorder

Anxiety occurs at times in most patients with cancer.¹⁴⁵ The diagnosis of cancer and the effects of the disease and its treatment are obvious sources of unease; however, anxiety may also be related to physiological aspects of the medical condition (eg, hormone-secreting tumors; effects of certain types of medications [bronchodilators]; withdrawal from alcohol or narcotics; pain or some other distressing physical symptom). Anxiety may not be severe or problematic, but

needs to be addressed when it becomes disruptive. After ruling out medical causes, the clinician should assess symptoms to determine the particular nature of the anxiety disorder(s). Generalized anxiety disorder is usually pre-existing and may be exacerbated by illness. Panic disorder may recur during illness in a person with previous panic symptoms. Post-traumatic stress disorder may develop after arduous cancer treatments or during a cancer treatment that triggers a traumatic memory of a past frightening event. Obsessive-compulsive disorder is a pre-existing disorder that results in difficulty in making decisions, ruminative thoughts about illness, and fearfulness to take medication. Some patients develop phobias of needles, hospitals, and blood or conditioned nausea/vomiting related to chemotherapy. Chemotherapy-induced nausea and vomiting should be managed according to the NCCN Guidelines for Antiemesis.

The NCCN Distress Management Panel recommends psychotherapy with or without an anxiolytic and/or an antidepressant for the treatment of anxiety (category 1), after eliminating medical causes. If the anxiety responds to initial treatment, follow-up should occur with the primary oncology team and family/caregivers. If no response is noted, the patient should be re-evaluated and treated with different medications (a neuroleptic should be considered) with continued psychotherapy, support, and education. If there is still no response, then the patient should be evaluated for depression and other psychiatric comorbidity.

The evidence for the effectiveness of these treatments has been reviewed.^{34,35} In a recent review in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer, Traeger et al¹⁴⁶ give a comprehensive description of the evidence for recommended pharmacologic and non-pharmacologic treatments for anxiety in patients with cancer.



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

Substance-Related Disorder/Abuse

Substance abuse is rare among cancer patients who do not have a history of active abuse or addiction to opioids, alcohol, or tobacco. Substance abuse or dependence developing during the course of the treatment may be due to insufficient symptom control and can be treated by improving symptom control. In patients with a history of substance abuse, its impact on cancer treatment should be assessed. After appropriate detoxification regimens, psychoeducation should be provided with or without cognitive-behavioral psychotherapy and with or without medication. Referral should be made to risk reduction, substance abuse management, or specialized treatment programs as needed. Patients with a history of substance abuse should be monitored for signs and symptoms of relapse.

Personality Disorder

Patients with cancer may have a pre-existing personality disorder, which can be exacerbated by the stress of cancer and its treatment.¹⁴⁷ When a personality disorder is suspected, the patient should be evaluated by a mental health professional, and safety and decision-making capacity should be assessed. If possible, any medication or other factors that could be aggravating the condition should be modified. A coordinated behavioral, psychological, and medical treatment plan, with or without medication, should be developed with the health care team.

Psychotic Disorder and Schizophrenia

Psychotic disorder includes hallucinations, delusions, and/or thought disorders; patients with recurrent psychotic episodes have schizophrenia. Psychotic disorder and schizophrenia can exist as comorbidities in patients with cancer and can also be caused or exacerbated by cancer and its associated stress and treatment. In

particular, steroids or steroid withdrawal can induce psychosis, which may be relieved by modifying dose or changing steroid choice.^{148,149} When a patient in a long-term psychiatric facility develops cancer, there is a need for coordination of care between the psychiatric facility and the inpatient cancer facility. Special attention should be paid to the transition of a psychiatric patient who needs inpatient oncology care. The issues around continuation of psychotropic medications, when they must be stopped for surgery or chemotherapy and when they should be restarted, are important issues in total care.

When a psychotic episode occurs in a patient with cancer, differential diagnoses must be ruled out. Delirium is often confused with psychotic disorder and is much more common; dementia, mood disorder, and substance abuse/withdrawal should also be considered. When psychotic disorder or schizophrenia is diagnosed, several interventions can be considered: 1) anti-psychotic medication, 2) medication for mood, 3) transfer to a psychiatric unit/hospital, and 4) electroconvulsive therapy (ECT) for psychotic depression/mania or catatonia.

In ECT, electrical currents are passed through the brain in a controlled fashion, inducing a brief seizure. ECT appears to be an effective treatment of psychotic depression, mania, catatonia, and other psychiatric disorders.¹⁵⁰⁻¹⁵⁴ Although the use of ECT in cancer has not been well studied, several case studies suggest that it can be safe and effective.¹⁵⁵⁻¹⁵⁹

Social Work and Counseling Services

Social work and counseling services are recommended when a patient has a psychosocial or practical problem. Practical problems are illness-related concerns; concrete needs (eg, housing, food, financial assistance, help with activities of daily living, transportation); employment, school, or career concerns; cultural or language issues;



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

and caregiver availability. The guidelines outline interventions that vary according to the severity of the problem.

Psychosocial problems are adjustment to illness; family conflicts and social isolation; difficulties in decision making; quality-of-life issues; concerns about advance directives; domestic abuse and neglect; poor coping or communication skills; concerns about functional changes (eg, body image, sexuality); and issues pertaining to end of life and bereavement (including cultural and caregiver concerns).

Social workers intervene in mild psychosocial problems by using patient and family education, support groups, and/or sex or grief counseling and by suggesting available local resources. For moderate to severe psychosocial problems, counseling and psychotherapy are used (including sex and grief counseling); community resources are mobilized; problem solving is taught; and advocacy, education, and protective services are made available.

Spiritual Care and Chaplaincy Services

Many patients use their religious and spiritual resources to cope with illness¹⁶⁰; many cite prayer as a major help. In addition, the diagnosis of cancer can cause an existential crisis, making spiritual support of critical importance. Balboni et al¹⁶¹ surveyed 230 patients with advanced cancer treated at multiple institutions who had failed to respond to first-line chemotherapy. The majority of patients (88%) considered religion as somewhat or very important. Nearly half of the patients (47%) reported receiving very minimal or no support at all from their religious community and 72% reported receiving little or no support from their medical system.¹⁶¹ Importantly, patients receiving spiritual support reported a higher quality of life. Religiousness and spiritual support have also been associated with improved satisfaction with medical care. Astrow et al¹⁶² found that 73% of patients with

cancer had spiritual needs, and that patients whose spiritual needs were not met reported lower quality of care and lower satisfaction with their care. A recent multi-institution study of 75 patients with cancer and 339 oncologists and nurses (the Religion and Spirituality in Cancer Care Study) found that spiritual care had a positive effect on patient-provider relationships and the emotional well-being of patients.¹⁶³

The panel has included chaplaincy services as part of psychosocial services. All patients should be referred for chaplaincy services when their problems are spiritual or religious in nature or when they request it. The panel identified 11 issues related to illness for which people often seek chaplaincy services. A treatment guideline is available for each of these issues: grief, concerns about death and the afterlife, conflicted or challenged belief systems, loss of faith, concerns with meaning and purpose of life, concerns about relationship with deity, isolation from the religious community, guilt, hopelessness, conflict between beliefs and recommended treatments, and ritual needs.

The certified chaplain evaluates the problem and may offer spiritual or philosophical reading materials, spiritual advice and guidance, prayer, and/or rituals. For patients who are members of a religious community, the certified chaplain could also serve as a liaison between the patient and the religious community or assist the patient to access spiritual resources. Some patients may be referred for social work and counseling or mental health services if the problems indicate a need for more than spiritual counseling. In addition, patients whose concerns are not allayed may be referred for mental health evaluation while continuing to receive spiritual counseling if they wish. In particular, patients who experience guilt or hopelessness should also be evaluated by mental health professionals for further assessment since they may also have severe depressive symptoms or suicidal ideations.



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

A palliative/supportive care consultation can also be important in patients who express hopelessness.

A consensus conference on improving the quality of spiritual care as a dimension of palliative care was held in February 2009. The report from this conference provides recommendations for health care professionals on the integration of spiritual care into the patient's overall treatment plan.¹⁶⁴ The inclusion of a certified chaplain in the interdisciplinary team is critical for the implementation of spiritual care into routine clinical practice.

The following guidelines on religion and spirituality in cancer care may be useful for clinicians and patients:

- National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Second Edition, 2009. These guidelines provide a framework to acknowledge the patient's religious and spiritual needs in a clinical setting. Spiritual, Religious, and Existential Aspects of Care are included as 1 of the 8 clinical practice domains in these guidelines: <http://www.nationalconsensusproject.org/guideline.pdf>.
- The National Cancer Institute's comprehensive cancer information database (PDQ) has information on "Spirituality in Cancer Care" for patients (<http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/Patient>) and for health care professionals (<http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional>).

Oncologist Burnout

The stress and demands of treating patients with cancer and making life and death decisions daily often cause psychologic distress for oncologists. This distress in turn can cause depression, anxiety, and fatigue. It can also cause burnout, characterized by a lack of

enthusiasm for work, feelings of cynicism, and a low sense of personal accomplishment with work, in as many as 28% to 38% of oncologists, as recently reviewed by Shanafelt and Dyrbye.¹⁶⁵ Burnout can affect medical care, physician-patient relationships, and personal relationships and can lead to substance abuse and even suicide. Strategies for avoiding and reducing burnout discussed in the review include training in self-care, personal wellness, mindful meditation, and behavioral change by medical schools, residency programs, hospitals, and private practices. Organizational strategies can also create a culture that is less stressful and less conducive of oncologist burnout.

The *Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer

In April 2012, the *Journal of Clinical Oncology* published a Special Series on psychosocial care (<http://jco.ascopubs.org/content/30/11.toc>), demonstrating that this topic is now getting the attention it has so long deserved. The Special Series includes a review by Jacobsen and Wagner that describes how the new standard of psychosocial care, the development of clinical practice guidelines for psychosocial care such as these NCCN guidelines, and the establishment of indicators to measure the quality of psychosocial care can help increase the number of patients with cancer receiving psychosocial care.¹⁶⁶ Integral to the successful integration of psychosocial care into routine cancer care is a distress screening program. In the Special Series, Carlson et al⁹⁰ present their recommendations for implementing such a program, and Fann et al⁵¹ discuss the organizational challenges of this new integrated care model, with a focus on the collaborative care service model.

Research on psychosocial care in cancer treatment has expanded greatly in recent years. This fact attests to the growing awareness of the importance of the topic, both by health care professionals and by the public.¹⁶⁷ The Special Series includes reviews of evidence-based



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

interventions for 3 common psychosocial problems in patients with cancer: depression, anxiety, and delirium.^{136,144,146}

Worries and concerns about cancer do not necessarily end with the end of acute care. The Special Series thus also includes articles addressing the psychosocial needs of adolescent and young adult (AYA) and adult cancer survivors.^{168,169} An article on the psychosocial needs of care givers is also included.¹⁷⁰

In addition, an article was included on 'oncologist burnout,' a problem with an estimated prevalence of 28% to 38%, depending on medical specialty.¹⁶⁵ The Special Series concludes with a review and meta-analysis of studies that provide evidence for the development of an appropriate curriculum for communication skills training of oncologists.⁹⁹ Patient benefit from such training (ex, better adherence to treatment) has yet to be demonstrated.

Summary

Psychosocial care is increasingly being recognized as an integral component of the clinical management of cancer patients. Treating distress in cancer benefits the patients and their families/caregiver as well as the treating staff and helps improve the efficiency of clinic operations. For patients with cancer, integration of mental health and medical services is critically important. Spirituality and religion also play an important role for many patients with cancer in coping with the diagnosis and the illness.

The NCCN Guidelines for Distress Management recommend that each new patient be rapidly assessed in the office or clinic waiting room for evidence of distress using the Distress Thermometer and Problem List as an initial rough screen.¹⁷¹ A score of 4 or greater on the DT should trigger further evaluation by the oncologist or nurse and referral to a

psychosocial service, if needed. The choice of which psychological service is needed is dependent on the problem areas specified on the Problem List. Patients with practical and psychosocial problems should be referred to social workers; those with emotional or psychological problems should be referred to mental health professionals including social workers; spiritual concerns should be referred to certified chaplains.

Health care contracts often allow these services to "fall through the cracks" by failing to reimburse for them through either behavioral health or medical insurance. Reimbursement for services to treat psychosocial distress must be included in medical health care contracts to prevent fragmentation of mental health services for the medically ill. Outcomes research studies that include quality-of-life assessment and analysis of cost-effectiveness are needed to help make this a reality.

The primary oncology team members (oncologist, nurse, and social worker) are central to making this model work. It is critical for at least one team member to be familiar with the mental health, psychosocial, and chaplaincy services available in the institution and the community. A list of the names and phone numbers for these resources should be kept in all oncology clinics and should be updated frequently.

Education of patients and families is equally important to encourage them to recognize that control of distress is an integral part of their total cancer care.



NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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NCCN Guidelines Version 2.2013 Distress Management

[NCCN Guidelines Index](#)
[Distress Management Table of Contents](#)
[Discussion](#)

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Appendix H

Comprehensive Psychosocial Assessment Chart Audit Instrument

Denise Sartz

Chart number:

Date Enrolled in Project:

Demographics:

Gender: Male Female

Age:

Oncologist: Batezini El-Tarabily Other

Ethnicity: Caucasian African American Hispanic Asian Other

Language spoken: English Spanish Other

Marital status: Single Married Widowed Divorced

Employment status: Retired Full time Part time Unemployed Student Disabled

Primary care provider: Yes No

Insurance: Medicare Medicaid Private Uninsured

Living Situation: Alone Spouse Extended Family Non-relatives Assisted Living
 Skilled Nursing Facility Other

Current Residence: Cheyenne Wheatland Torrington Kimball Laramie Other

Religion: Catholic LDS Presbyterian Lutheran Christian Jewish None Other

Diagnosis & Treatment History:**Cancer Diagnosis:**

Date of Diagnosis: Month: Year:

Stage: I II III IV Unknown Not Applicable

Chemotherapy Treatment:

Treatment Goal: Palliative Curative Unknown

| | | | | | | | |
|---|-------|--------|-------|--------|--------------|---------|-------|
| Line of Treatment: | First | Second | Third | Fourth | Five or more | | |
| Concomitant Radiation: | Yes | No | | | | | |
| Comorbid Conditions: | CHF | COPD | DM | CVA | OA | CAD | Other |
| Baseline ECOG performance score: | 0 | 1 | 2 | 3 | 4 | Unknown | |

| | | | | | |
|----------------------|-----------|--------|-----------|-----------|----------|
| NCCN Distress Score: | | | | | |
| Category: | Practical | Family | Emotional | Spiritual | Physical |
| Date of Score: | | | | | |
| ECOG: 0 | 1 | 2 | 3 | 4 | |
| Intervention: | | | | | |

| | | | | | |
|----------------------|-----------|--------|-----------|-----------|----------|
| NCCN Distress Score: | | | | | |
| Category: | Practical | Family | Emotional | Spiritual | Physical |
| Date of Score: | | | | | |
| ECOG: 0 | 1 | 2 | 3 | 4 | |
| Intervention: | | | | | |

| | | | | | |
|----------------------|-----------|--------|-----------|-----------|----------|
| NCCN Distress Score: | | | | | |
| Category: | Practical | Family | Emotional | Spiritual | Physical |
| Date of Score: | | | | | |
| ECOG: 0 | 1 | 2 | 3 | 4 | |
| Intervention: | | | | | |

| | | | | | |
|----------------------|-----------|--------|-----------|-----------|----------|
| NCCN Distress Score: | | | | | |
| Category: | Practical | Family | Emotional | Spiritual | Physical |
| Date of Score: | | | | | |
| ECOG: 0 | 1 | 2 | 3 | 4 | |
| Intervention: | | | | | |

| | | | | | |
|----------------------|-----------|--------|-----------|-----------|----------|
| NCCN Distress Score: | | | | | |
| Category: | Practical | Family | Emotional | Spiritual | Physical |
| Date of Score: | | | | | |
| ECOG: 0 | 1 | 2 | 3 | 4 | |
| Intervention: | | | | | |

| | | | | | |
|----------------------|-----------|--------|-----------|-----------|----------|
| NCCN Distress Score: | | | | | |
| Category: | Practical | Family | Emotional | Spiritual | Physical |
| Date of Score: | | | | | |
| ECOG: 0 | 1 | 2 | 3 | 4 | |
| Intervention: | | | | | |

Information and referral interventions provided after DT scores obtained:**HO:** Handout (resources available in community) provided**R:** Referral Options: Nurse Practitioner, Hospice, Lymphedema, Nutrition, Psych, Chaplain, Social Worker, Meals on Wheels, Patient Navigator, Financial Counselor, Palliative Care, Home Care, Wound Care, Oncologist, Primary Care Physician, PT/OT, Patient Refused Referral, Other**Emergency Room Visits During Treatment:**

Yes

No

Dates (if applicable): _____

Reason: _____

Hospitalizations During Treatment:

Yes

No

Dates (if applicable): _____

Admitting Diagnosis: _____

Length of Stay: _____

Project Status:

Completed

Withdrawn by investigator

Patient Withdrew

Deceased

Participation Completion Date: _____

CITI Collaborative Institutional Training Initiative

Human Research Curriculum Completion Report Printed on 7/31/2012

Learner: Denise Sartz (username: denisesartz)

Institution: Regis University

Contact

Department: Nursing

Information

Email: sartz158@regis.edu

Social Behavioral Research Investigators and Key Personnel:

Stage 1. Basic Course Passed on 07/31/12 (Ref # 8379770)

| Required Modules | Date Completed | |
|--|----------------|------------|
| Introduction | 07/31/12 | no quiz |
| History and Ethical Principles - SBR | 07/31/12 | 4/5 (80%) |
| The Regulations and The Social and Behavioral Sciences - SBR | 07/31/12 | 5/5 (100%) |
| Assessing Risk in Social and Behavioral Sciences - SBR | 07/31/12 | 5/5 (100%) |
| Informed Consent - SBR | 07/31/12 | 5/5 (100%) |
| Privacy and Confidentiality - SBR | 07/31/12 | 4/5 (80%) |
| Regis University | 07/31/12 | no quiz |

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Course Coordinator

[Return](#)



Appendix J

January 18, 2013

Denise A. Sartz, MS
Cheyenne Regional Medical Center
214 East 23rd Street
Cheyenne, WY 82001

RE: NEIRB# 13-018: "Screening for Distress in Ambulatory Oncology Patients"

Dear Dr. Sartz:

This is to inform you that New England Institutional Review Board (NEIRB) has reviewed the submission for the above-captioned project.

NEIRB has determined that this activity, as conducted at the above location, is not seeking to obtain generalizable knowledge. Therefore, it is not human subjects research and IRB review and approval is not required.

Please call me if you have any questions about the terms of this determination.

A handwritten signature in black ink that reads "Erin Brower". The signature is written in a cursive, flowing style.

Erin Brower, MS, CIP
Director

Copy: NEIRB Chair



Academic Affairs
Academic Grants

3333 Regis Boulevard, H-4
Denver, Colorado 80221-1099

303-458-4206
303-964-5528 FAX
www.regis.edu

Appendix K

IRB – REGIS UNIVERSITY

February 18, 2013

Denise Sartz
2718 Stockbury Drive
Fort Collins, CO 80525

RE: IRB #: 13-043

Dear Ms. Sartz:

Your application to the Regis IRB for your project "Screening for Distress in Ambulatory Oncology Patients: The COPE Project" was approved as an exempt study on February 13, 2013. This study was approved under the 45CFR46.101.b exempt study category #2.

The designation of "exempt," means no further IRB review of this project, as it is currently designed, is needed.

If changes are made in the research plan that significantly alter the involvement of human subjects from that which was approved in the named application, the new research plan must be resubmitted to the Regis IRB for approval.

Sincerely,

Patsy McGuire Cullen, PhD, CPNP
Chair, Institutional Review Board
Associate Professor and Director
Department of Accelerated Nursing
Loretto Heights School of Nursing
Rueckert-Hartman College for Health Professions
Regis University

cc: Dr. Diane Ernst

Appendix L



Cheyenne Regional Medical Center

214 East 23rd Street
Cheyenne, WY 82001
307-634-2273
www.crmcwy.org

January 21, 2013

Institutional Review Board
Regis University
Main Hall, Room 452, Mail Code H4
Denver, CO 80221
Email: irb@regis.edu

RE: Denise Sartz, FNP-C, Doctoral Research

To Whom It May Concern:

As the Chief Compliance and Privacy Officer, this letter is to serve as notice that Cheyenne Regional Medical Center supports the project proposed by Denise Sartz, FNP-C, entitled "Screening for Distress in Ambulatory Oncology Patients". Cheyenne Regional is pleased to support Ms. Sartz in her academic endeavors and we anticipate the results of her research.

For this study, Cheyenne Regional understands that Ms. Sartz will have patients complete a short questionnaire during each chemotherapy visit and using that information, see if putting people in touch with resources will improve their overall well-being. This project has been approved by our outside Institutional Review Board, New England IRB. We anticipate that if the scope of the study is to change that Ms. Sartz will notify Cheyenne Regional in advance of the change to determine if additional institutional safe guards need to be followed.

If you have any additional questions or concerns, please contact Aimee Dendrinis, Compliance Counsel at (307) 432-6624 or aimee.dendrinis@crmwy.org.

Thank you,

Carlene Crall
Chief Human Resources Officer
Chief Compliance Officer

Appendix M
Cheyenne Regional Medical Center
Oncology Product Line
Psychosocial Distress Screening Policy

2012 Standard E10: Psychosocial Distress Screening

Rationale:

Distress (defined): A multifactorial, unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (NCCN, 2012). Oncology patients frequently present with complex physical needs as well as overwhelming unmet psychosocial concerns. It has been estimated that 40-50% of adults with cancer experience clinically significant levels of distress (Jacobsen, Donovan, and Trask, 2005). In addition, it has been demonstrated that patients with heightened distress have poorer treatment outcomes, poorer quality of life and overall poor satisfaction with care (Jacobsen & Ransom, 2007). In response to these needs the National Comprehensive Cancer Network (NCCN) issued evidenced-based guidelines to help clinicians identify, assess, and treat unmet spiritual, psychological, practical, and physical problems.

Policy:

As agreed upon by the Cheyenne Regional Medical Center Cancer Committee, oncology patients will be screened and assessed for distress utilizing the NCCN Distress Thermometer (Comprehensive Oncology Patient Experience (COPE) Tool).

All patients will be screened and assessed for distress at their initial visit, at appropriate intervals, and as clinically indicated, especially when changes occur in disease status (remission, recurrence, or progression). At a minimum, a baseline assessment will be completed prior to beginning chemotherapy/radiation therapy and again as deemed clinically necessary.

Procedure:

All oncology patients and their caregivers will be provided information about the psychosocial services available at Cheyenne Regional Medical Center and within the community. Clinical evidence of a moderate to severe distress score (≥ 4) on the NCCN distress thermometer requires a clinical assessment by a member of the primary oncology team (oncologist, nurse practitioner, clinical nurse specialist, registered nurse, or social worker). Patients with a moderate to severe distress score will be referred to a mental health specialist, social worker, or chaplain depending on the problems identified on the problem list. Distress assessments, interventions, and referrals are documented in the patient medical record to facilitate integrated, high quality care by the multi-disciplinary team.

References:

- Jacobsen, P., Donovan, K., and Trask, P. (2005). Screening for psychologic distress in ambulatory care cancer patients. *Cancer*, 103, 1494-1502.
- Jacobsen, P., & Ransom, S. (2007). Implementation of NCCN distress management guidelines by member institutions. *Journal of the National Comprehensive Cancer Network*, 5, 99-102.
- National Comprehensive Cancer Network (2012). *Distress management*. Version 2.2012.
- Retrieved from: www.nccn.org.

Appendix N

Electronic Health Record Integration

| COPE Assessment - COPE Assessment Based on Past Week (To be completed monthly) | |
|--|------------------------|
| Time taken: | 0810 7/18/2013 |
| Responsible | Create Note |
| Psychiatric | |
| Distress | 10 9 8 7 6 5 4 3 2 1 0 |
| Practical Problems | |
| Child Care | 1=Yes 2=No |
| Housing | 1=Yes 2=No |
| Insurance / Financial | 1=Yes 2=No |
| Transportation | 1=Yes 2=No |
| Work / School | 1=Yes 2=No |
| Treatment Decisions | 1=Yes 2=No |
| Family Problems | |
| Dealing with children | 1=Yes 2=No |
| Dealing with partner | 1=Yes 2=No |
| Ability to have children | 1=Yes 2=No |
| Family health issues | 1=Yes 2=No |