

Coleman Supportive Oncology Initiative

Distress Training Module

Topic: The Impact of Distress on Patient Care

Presenters: Frank J. Penedo, PhD and James Gerhart, PhD
updated by Christine B. Weldon, MBA; Julia R. Trosman PhD and Betty Roggenkamp, BA

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Learning Objectives

By the end of this module you should be able to:

- 1. Define stress, distress and depression**
- 2. Identify sources of distress and why it warrants screening**
- 3. Explain the impact of distress on cancer treatment and quality of life, and how to treat this distress**

Stress, Distress and Depression Defined

The National Cancer Institute (NCI) defines stress, distress and depression as follows:

Stress – “In medicine, the body’s response to physical, mental, or emotional pressure. Stress causes chemical changes in the body that can raise blood pressure, heart rate, and blood sugar levels. It may also lead to feelings of frustration, anxiety, anger, or depression. Stress can be caused by normal life activities or by an event, such as trauma or illness. Long-term (chronic) stress or high levels of stress may lead to mental and physical health problems.”

Distress – “Emotional, social, spiritual, or physical pain or suffering that may cause a person to feel sad, afraid, depressed, anxious, or lonely. People in distress may also feel that they are not able to manage or cope with changes caused by normal life activities or by having a disease, such as cancer. Cancer patients may have trouble coping with their diagnosis, physical symptoms, or treatment.”

Depression – “A mental condition marked by ongoing feelings of sadness, despair, loss of energy, and difficulty dealing with normal daily life. Other symptoms of depression include feelings of worthlessness and hopelessness, loss of pleasure in activities, changes in eating or sleeping habits, and thoughts of death or suicide. Depression can affect anyone, and can be successfully treated. Clinically elevated depression affects 15-25% of cancer patients” versus 7% of the U.S. population, age 18 and older, in a given year.

Standards and Guidelines for Distress Screening and Treatment

Given the implications for adjustment, adherence and outcomes, the Commission on Cancer and other national bodies now call for routine distress screening:

- Screening patients for distress and psychosocial health needs is a critical first step to providing high-quality cancer care.
- Distress should be recognized, monitored, and documented and treated promptly at all stages of the disease.
- All patients with cancer need to be *referred for the appropriate provision of care*; high-quality psychosocial cancer care includes a systematic follow-up and reevaluation.

Sources of Distress

Fear, uncertainty and stigma

- Cancer can be a frightening experience.
 - Hopelessness about the disease
 - Anxiety about possible outcomes
 - Concerns that support systems do not understand
- Patients may experience distress as a result of disease monitoring, treatment related side effects, uncertainty about the future, financial burden and physical limitations
- “Cancer” itself remains a stigmatized condition, particularly for some specific racial/ethnic minorities.
- Survivors, even those with a good prognosis, may fear cancer recurrence.

Biological

- Pain and distress may create a negative spiral
 - In advanced disease, pain may contribute to a desire for hastened death.
- Cancer treatments and stress can exacerbate symptom burden via their effects on endocrine and immune systems, inflammation and CNS physiology known to regulate mood.

How Common is Distress?

- **Distress is very common, but it ranges in severity.**
 - 25% - 33% of cancer patients are distressed versus 7% of the general population
- **Stress associated with cancer and its treatment may trigger clinical levels of distress, such as:**
 - Major depression, marked by depressed mood, hopelessness and anhedonia
 - Posttraumatic Stress Disorder (PTSD), marked by reliving trauma, avoidance and increased arousal
- **Cancer may exacerbate pre-existing anxiety, depression and trauma**
 - Patient stress may be "kindled" by past experiences but then exacerbated by cancer

Stress Reactions

- **Stress is a normative response when life, resources and values are threatened.**
 - Stress is experienced when the demands placed by a stressor (e.g., negative life event) outweigh the patients' resources to cope with that event.
 - Cancer is viewed as a chronic stressor that threatens life, resources and values and leads to distress.
 - Since cancer is a long-term chronic stressor, it demands ongoing access to coping resources (e.g., social support, information, relaxation).
- **Most patients experience some distress at some point during their care.**
 - Diagnosis, treatment and progression points are commonly the most distressing periods for cancer patients.
- **Patient background, experience and value systems impact how they respond to distress. Shock, disbelief, anger and sadness are common.**
- **While most patients adjust relatively well, patients with premorbid mental health conditions, advanced disease and poor prognosis experience the most distress.**

Distress' Impact and the Need to Screen for Distress

- **Distress, along with chronic stress, can negatively impact health outcomes via their effects on physiological mechanisms (e.g., immunity).**
- **Distress can impact patients' medical decisions and adherence to treatment.**
- **Cancer can be frightening to patients and their families.**
- **Rates of suicide are doubled among patients with cancer.**
- **Cancer can be painful and reduce many aspects of quality of life (e.g., social, emotional and functional), which may cause distress.**
- **Distress can be effectively treated by understanding, empathizing and providing necessary referrals to psychosocial services.**

Stress' Impact on Health Outcomes

- **A meta-analysis of 76 studies found that depression is associated with mortality across disease types.**
- **Stress and related processes may trigger inflammation and immune dysregulation across populations.**
 - Impaired natural killer cell (NKC) lysis following breast surgery
 - NKC cytotoxicity in prostate cancer
 - Poorer recovery of blood counts following stem cell transplant
 - Potentially increased risk of disease progression and opportunistic infections
- **Cancer is associated with a two-fold risk in suicide.**
 - Patients may be simultaneously fighting for their lives, and contemplating ending their lives.
 - Risk factors include:
 - Being older
 - Being male
 - Being unmarried
 - Having advanced disease
 - Having lung, stomach, head and neck cancer

Distress, Impact on Communication and Decision-Making

- **Mental health concerns are not often identified in medical settings.**
 - Patients may be too scared to ask for help.
 - Providers may worry that asking about their stress will only make it worse.
 - Providers may have limited resources.

- **Shock, worry and anxiety make communication harder**
 - Patients may be too overwhelmed to concentrate.
 - Patients may be too irritable and may push others away.

- **Stress can impact patients' decision-making.**
 - Depression triples the risk of general medical non-adherence.
 - Patients weigh emotions and well-being heavily when making decisions.
 - Some patients believe that treatments will not work.
 - Some patients overestimate the negative impact of side effects.
 - Patients may learn to avoid upsetting places or situations that trigger flight/fight stress responses which may cause them to avoid treatment follow-up and compliance.
 - Lack of energy or poor concentration can make it more difficult:
 - For patients to make and remember appointments
 - For patients to plan for the future, which can also interfere with treatment compliance

Treating Distress

- **Good patient – provider communication may be the first intervention.**
- **Non-pharmacological therapies such as cognitive behavioral therapy and relaxation techniques**
 - Problem-solving
 - Coping and communication skills
 - Optimizing efficacious social networks
 - Psychoeducation
 - Understanding stress responses and links to behavior and emotions
 - Relaxation strategies such as deep breathing and mindfulness-based meditation
 - Spiritual support
 - Exercise
- **Pharmacotherapies**
 - SSRIs: sertraline, citalopram, escitalopram

Summary of Points Covered

In this training module we addressed:

- **Cancer is stressful**
- **Patients may internalize their emotions, shut down, push others away and avoid what they need most.**
 - As a result, patients may feel less supported than they could be.
- **Not effectively addressing their psychosocial, practical and physical concerns can compromise adjustment and health outcomes.**
- **Effective treatments are available but intervention begins with assessing and addressing symptoms on a routine basis.**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network®

➤ [NCCN Clinical Guidelines®](#)

http://www.nccn.org/professionals/physician_gls/f_guidelines.asp

Institute of Medicine

➤ [Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs](#)

<https://iom.nationalacademies.org/Reports/2007/Cancer-Care-for-the-Whole-Patient-Meeting-Psychosocial-Health-Needs.aspx>

ONCOTALK

➤ [Improving oncologist's communication skills](#)

<http://depts.washington.edu/oncotalk/learn/>

Faculty Bio for Frank J. Penedo, PhD

Dr. Frank J. Penedo is the Roswell Park Professor of Medical Social Sciences, Psychology and Psychiatry and Behavioral Sciences. He is also the Program Leader of the Cancer Control and Survivorship Program in the Lurie Cancer Center and the Director of the Cancer Survivorship Institute at Northwestern Medicine. He is trained in clinical psychology and behavioral medicine and his research has focused on evaluating the role of psychosocial, sociocultural and biobehavioral processes in adjustment, health related quality of life (HRQOL) and health outcomes in chronic disease populations with a major emphasis on diverse cancer survivors in regard to race, ethnicity and socio-economic status. Dr. Penedo has served as PI, co-PI or project leader on multiple NIH-funded studies addressing psychosocial and biobehavioral correlates of adjustment and the efficacy of psychosocial interventions in improving HRQOL, symptom burden and health outcomes in chronic disease populations. He has significant expertise in community based, cohort and intervention studies that target cancer survivors and involve collection and analyses of psychosocial and biological data. He has over 110 peer-reviewed publications, has served as associate editor of two major journals in his field, and some of his translational work has been disseminated as clinical intervention tools. Dr. Penedo currently serves as a standing member of the NIH BMIO study section and on the editorial board of several major journals in his field. He is the president elect of the International Society of Behavioral Medicine, a fellow of the Society of Behavioral Medicine and a member of the Academy of Behavioral Medicine Research. He has received numerous awards and also served on the advisory boards of community organizations such as the Wellness Community, the Intercultural Cancer Council and Salud America.

Link to website with additional information about the faculty member:

<http://www.feinberg.northwestern.edu/faculty-profiles/az/profile.html?xid=24719>

Faculty Bio for James Gerhart, PhD

Dr. Gerhart is an assistant professor and licensed clinical psychologist at the Rush Cancer Center.

His research focuses on stress related to chronic illnesses including cancer. Dr. Gerhart is particularly interested in the ways that family and professional caregivers respond when patients express their emotions about cancer. His current projects include the Coleman Supportive Oncology Initiative, and enhancing resilience among professional caregivers.

For additional information:

https://www.researchgate.net/profile/James_Gerhart

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Coleman Supportive Oncology Initiative

Distress Training Module

Topic: How to Conduct a Supportive Care Screening (Including Distress)

Presenters: Jennifer C. Obel, MD and Christine Weldon, MBA,
updates provided by Betty Roggenkamp, BA

Learning Objectives

By the end of this module you should be able to:

- 1. Explain which guidelines and instruments inform various sections of a supportive oncology screening (distress) tool**
- 2. Describe the appropriate timing and frequency of the supportive oncology (distress) screening tool**
- 3. Discuss examples of how different healthcare organizations have used the supportive oncology (distress) screening tool**

The purpose of supportive oncology screening is to identify a patient's potential supportive oncology needs.

The screening components consist of:

- Distress/Anxiety
- Health Literacy
- Practical Concerns
- Self Care Concerns
- Family/Caregiver Concerns
- Spiritual/Faith/Religious Concerns
- Nutrition
- Treatment or Care Concerns
- Physical Concerns
- Pain
- Fatigue/Low Energy
- Physical Activity/Function

Supportive Care Screening Tool Example (con't.)

Over the **last 14 days**, how often have you been bothered by the following problems? ¹

Please mark one box per row

	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Instruments and guidelines used for creation of: Distress/Anxiety screening section

- The PHQ-4 tool was selected based on the ASCO's 2014 Distress Guidelines (Andersen BA, JCO 2014).
- PHQ-4's purpose is to allow for very brief and accurate measurement of depression and anxiety.
- PHQ-4 is a 4 item inventory rated on a scale. Its items are drawn from the "Generalized Anxiety Disorder-7 scale" and the "Patient Health Questionnaire-9"
- The PHQ-4 developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues.

Supportive Care Screening Tool Example (con't.)

	YES	NO ¹¹
Do you need someone like a family member, friend or clinic worker to help you read hospital materials?	<input type="checkbox"/>	<input type="checkbox"/>
Do you need help when filing out medical forms by yourself?	<input type="checkbox"/>	<input type="checkbox"/>

Health Literacy Screening

- Adapted from Cornett, S., (Sept. 30, 2009) "Assessing and Addressing Health Literacy" OJIN: The Online Journal of Issues in Nursing Vol. 14, No. 3, Manuscript 2.

Practical Concerns ^{2, 9}		
YES	NO	
<input type="checkbox"/>	<input type="checkbox"/>	Child care issues
<input type="checkbox"/>	<input type="checkbox"/>	Issues paying for food
<input type="checkbox"/>	<input type="checkbox"/>	Issues paying for housing
<input type="checkbox"/>	<input type="checkbox"/>	Issues with transportation to/from treatment
<input type="checkbox"/>	<input type="checkbox"/>	Work / school issues
<input type="checkbox"/>	<input type="checkbox"/>	Insurance coverage issues or no health insurance
<input type="checkbox"/>	<input type="checkbox"/>	Paying for medication or medical care
<input type="checkbox"/>	<input type="checkbox"/>	I live alone

Practical Concerns

- Based on the NCCN Problem List*, with an expansion of the financial concerns. Included "I live alone" from ASCO Distress Guidelines.

*The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Distress Management (Version 2.2018). Available at: NCCN.org. Accessed August 28, 2018; Andersen BL, et al JCO 2014.

Supportive Care Screening Tool Example (con't.)

Self Care Concerns¹⁰

Are you concerned about having someone available to help if:

YES NO

- | | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | You cannot get out of bed? |
| <input type="checkbox"/> | <input type="checkbox"/> | You feel sick and cannot do daily chores? |
| <input type="checkbox"/> | <input type="checkbox"/> | You cannot run errands? |

Self Care Concerns

- Adapted from the PROMIS Item Bank Instrumental Support – Short Form 4a, adjusted questions to Yes/No options.

YES	NO	<u>Family/Caregiver Concerns²</u>
<input type="checkbox"/>	<input type="checkbox"/>	Concerns about my children
<input type="checkbox"/>	<input type="checkbox"/>	Concerns about my partner
<input type="checkbox"/>	<input type="checkbox"/>	Concerns about caregivers
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children
<input type="checkbox"/>	<input type="checkbox"/>	Concerns about other family members

Family/Caregiver Concerns

- Based on the NCCN Problem List* with minor adaptation

* The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Distress Management (Version 2.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed August 28, 2018.

Supportive Care Screening Tool Example (con't.)

Spiritual / Faith / Religious Concerns⁵

YES NO

☐☐

Do you struggle with the loss of meaning and joy in your life?

☐☐

Do you have religious or spiritual struggles?

Spiritual/Faith/Religious Concerns

- Based on the NCCN Problem List*, with an expansion informed by FACIT-Spirituality

I would like to talk to someone about my “yes” checks above from Practical, Self Care, Family/Caregiver or Spiritual Concerns

YES ☐ NO ☐

I would like to talk to someone...

- Based on guidance / experience gained from Coleman Supportive Oncology Collaborative participants. If the patient/caregiver does not want to talk to someone, information is provided on the concerns noted.

*The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Distress Management (Version 2.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed August 28, 2018; The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Palliative Care (Version 1.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed August 28, 2018

Supportive Care Screening Tool Example (con't.)

Physical and Other Concerns ²

YES NO

- | | | |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Diarrhea |
| <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Nausea or vomiting |
| <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Difficulty chewing or swallowing |
| <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| <input type="checkbox"/> | <input type="checkbox"/> | Dry mouth |
| <input type="checkbox"/> | <input type="checkbox"/> | Dental/teeth issues |
| <input type="checkbox"/> | <input type="checkbox"/> | Cough |
| <input type="checkbox"/> | <input type="checkbox"/> | Swollen arms or legs |
| <input type="checkbox"/> | <input type="checkbox"/> | Feeling full quickly or swollen abdomen |
| <input type="checkbox"/> | <input type="checkbox"/> | Sexual intimacy or function |
| <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy, blister/pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |
| <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Use of tobacco/cigarettes/vaping |
| <input type="checkbox"/> | <input type="checkbox"/> | Use of alcohol/drugs |
| <input type="checkbox"/> | <input type="checkbox"/> | Difficulty concentrating |
| <input type="checkbox"/> | <input type="checkbox"/> | Difficulty remembering things |
| <input type="checkbox"/> | <input type="checkbox"/> | Difficulty finding the words I want to say |

Physical Concerns

- Based on the NCCN Problem List*, with an expansion of additional side effects and symptoms that often impact the patient's quality of life.
- The last 3 items informed by NCCN Guidelines[®] for Older Adult Oncology* and by ASCO Geriatric Guidelines released in 2018.

*The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) Distress Management (Version 2.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed August 28, 2018; The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) Older Adult Oncology (Version 1.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed [August 28, 2018]; Munoz, A. R., Cancer (2015)

Supportive Care Screening Tool Example (con't.)

YES	NO	<u>Nutrition Concerns</u> ^{2, 3}
<input type="checkbox"/>	<input type="checkbox"/>	Weight loss or lack of appetite
<input type="checkbox"/>	<input type="checkbox"/>	Weight gain
<input type="checkbox"/>	<input type="checkbox"/>	Issues with taste
<input type="checkbox"/>	<input type="checkbox"/>	Concerns about nutrition and food

Nutrition Concerns

- Based on the NCCN Problem List* and concepts from the MNA-SF (Mini Nutritional Assessment short-form): Kaiser, M.J., et al., Validation of the Mini Nutritional Assessment short-form (MNA-SF): a practical tool for identification of nutritional status. J Nutr Health Aging, 2009.

Supportive Care Screening Tool Example (con't.)

Pain⁶	In the past 7 days, have you been in pain?				
<input type="checkbox"/> NO	If NO, skip to <u>"Fatigue/Low Energy"</u>				
<input type="checkbox"/> YES	If YES, please mark one box per row below				
	No pain	Mild	Moderate	Severe	Very Severe
In the past 7 days how intense was your pain at its worst?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 7 days how intense was your average pain?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What is your level of pain right now?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Pain

- To address pain screening recommendations from NCCN, ASCO and IOM, this section utilized the pain question from the NCCN Problem List*.
- The PROMIS Pain Intensity Short Form 3a was added to assess the the patient's pain level.

*The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Distress Management (Version 2.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed August 28, 2018; Cella, D., Med Care (2007); Cella, D., Qual Life Res (2014).

Supportive Care Screening Tool Example (con't.)

Fatigue/Low Energy

Please mark one box per row ⁷

	Not at all	A little bit	Somewhat	Quite a bit	Very much
During the past 7 days I feel fatigued (low energy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
During the past 7 days I have trouble <u>starting</u> things because I am tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 7 days how run-down did you feel on average?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 7 days how fatigued were you on average?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Fatigue/Low Energy

- To address palliative care recommendations from NCCN, ASCO and IOM, and informed by the fatigue item on the NCCN Problem List*, utilized the PROMIS Fatigue Short Form 4a.
- PROMIS Fatigue Short Form/Instruments evaluate a range of self-reported symptoms, from mild subjective feelings of tiredness to an overwhelming, sustained sense of exhaustion that likely decreases one's ability to carry out daily activities and function normally in family or social roles.

*The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Distress Management (Version 2.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed August 28, 2018; Cella, D. Qual Life Res , (2014); Cella, D. Med Care (2007)

Supportive Care Screening Tool Example (con't.)

Physical Activity ⁸ <i>Please mark one box per row</i>	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
Are you able to do chores such as vacuuming or yard work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you able to go up and down stairs at a normal pace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you able to run errands and shop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you able to be out of bed most of the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you able to take care of your personal needs (dress, comb hair, toilet, eat, bathe)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Falls				YES	NO
Have you had 2 or more falls in the past 6 months? ¹				<input type="checkbox"/>	<input type="checkbox"/>
Have you been injured by a fall that required medical attention in the last 6 months?				<input type="checkbox"/>	<input type="checkbox"/>
Do you feel unsteady when walking? ¹²				<input type="checkbox"/>	<input type="checkbox"/>

Physical Activity

- To address palliative care recommendations from NCCN, ASCO and IOM, and informed by the “Loss of interest in usual activities” question from the NCCN Problem List*; utilized the PROMIS Physical Function Short Form 4a and added two questions from the PROMIS item bank to elicit ECOG status. The PROMIS item bank includes sets of well-defined and validated items, which can be used to derive short forms (typically requiring 4-10 items per concept).
- Added 3 questions about Falls informed by the ASCO Geriatric Guidelines and adapted from Phelan EA et al

*The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Distress Management (Version 2.2018). Available at: [NCCN.org](https://www.nccn.org). Accessed August 28, 2018; Jensen, R. E., (2015); Qual Life Res; Cella, D. Med Care (2007); Cella, D., (2014); Oken M, *Am J Clin Oncol* (1982); Phelan EA et al, MCNA 2014.

Supportive Care Screening Tool Example (con't.)

Treatment or Care Concerns⁴ *Please please check Yes or No for each*

YES NO

- | | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | I want to better understand my cancer diagnosis or stage. |
| <input type="checkbox"/> | <input type="checkbox"/> | I want to better understand my prognosis or long term outcome. |
| <input type="checkbox"/> | <input type="checkbox"/> | I have concerns or questions about my treatment options, medication, or my plan of care. |
| <input type="checkbox"/> | <input type="checkbox"/> | I want help discussing, with my family and friends, my treatment options and what is important to me.
• Do you have a Health Care Power of Attorney? YES <input type="checkbox"/> NO <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | I want help discussing and deciding on the kinds of medical care I want or don't want with my family, friends or doctor
• Do you have an Advance Medical Directive/Living Will? YES <input type="checkbox"/> NO <input type="checkbox"/> |

Treatment or Care Concerns

- This section was developed in accordance with the Institute of Medicine's 2013 report "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis" and NCCN Palliative Care Guidelines.

Timing and Frequency of the Supportive Oncology Screening Tool

The Commission on Cancer (standard 3.2) requires distress screening at pivotal points in care.

Suggested timing and frequency of supportive oncology screening includes:

- **Screening patients within 30 days of diagnosis**
- **Screening patients every 30 days during active treatment (associated with a physician or treatment appointment)**
 - Ideally, patients are screened at every transition point in care. However, it is difficult to identify pivotal care points in medical records. Therefore, an “every 30 day” approach was devised.
- **At survivorship transition and within 90 days of the last treatment**

Example of Supportive Oncology Screening Workflow in an Academic Hospital and Large Community Health System

- **The patient fills out the supportive oncology screening tool on a touch screen tablet or paper copy while in the waiting room.**
- **The medical assistant briefly reviews the screening tool with the patient, as if it were a part of vital signs.**
- **The medical assistant enters the results into an electronic medical record (EMR) template.**
 - Answers to the 4 Distress/Anxiety questions
 - Responses that elicit a symptom or concern require follow up
 - Answers to the Pain, Fatigue and Physical Activity questions
- **The EMR then creates suggested activities/actions (alerts) to address the patient's concerns**

Ex: A referral to a social worker to address practical concerns, or a referral to palliative specialist to address uncontrolled symptoms

Example of Supportive Oncology Screening Workflow in Large Publicly Funded Health System

- **The patient fills out the screening tool on a touch screen tablet with audio support available for low health literacy; also available in Spanish.**
- **A social worker reviews the report with results from the distress/anxiety, practical, family/caregiver and spiritual sections then follows up with the patient.**
- **The treating nurse or physician reviews the report with results from nutrition, treatment/care concerns, physical, pain, fatigue and physical activity sections and follows up with the patient.**
- **This site is considering assessing longitudinal shifts in patient's pain, fatigue and/or physical activity results as a reason for sub-specialty palliative care involvement or referral.**

Example of Supportive Oncology Screening Workflow in a Safety Net Hospital System

- **The patient fills out paper the supportive oncology screening tool in the waiting room or infusion center; also available in Spanish.**
- **A staff member (navigator, medical assistant or nurse) reviews the supportive oncology screening tool.**
 - If any distress/anxiety score is “nearly every day,” immediate action is taken by paging a social worker.
 - If any pain score is “severe or very severe,” immediate action is taken by paging the treating physician.
- **The social worker reviews results from the distress/anxiety, practical, family/caregiver and spiritual sections and follows up with patient.**
- **The treating nurse/physician reviews the results from the nutrition, treatment/care concerns, physical, pain, fatigue and physical activity sections and follows up with patient.**

In this training module we addressed:

- **Which guidelines and instruments inform various sections of a Supportive Oncology Screening Tool**
- **The appropriate timing and frequency of the Supportive Oncology Screening Tool**
- **Examples of how different healthcare organizations have used a Supportive Oncology Screening Tool**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network®

- [NCCN Clinical Guidelines®- Distress Management, Version 2.2018](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf)
http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf
- [NCCN Clinical Guidelines®- Palliative Care, Version 1.2018](http://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf)
http://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf
- [NCCN Clinical Guidelines®- Older Adult Oncology, Version 1.2018](https://www.nccn.org/professionals/physician_gls/pdf/senior.pdf)
https://www.nccn.org/professionals/physician_gls/pdf/senior.pdf

American Society of Clinical Oncology ASCO®

- [Palliative Care in Oncology](http://www.asco.org/practice-research/palliative-care-oncology)
http://www.asco.org/practice-research/palliative-care-oncology

ASCO Institute for Quality™

- [Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation](http://www.instituteforquality.org/screening-assessment-and-care-anxiety-and-depressive-symptoms-adults-cancer-american-society)
http://www.instituteforquality.org/screening-assessment-and-care-anxiety-and-depressive-symptoms-adults-cancer-american-society

PROMIS®

- [Patient Reported Outcomes Measurement Information System](http://www.nihpromis.org/about/overview?AspxAutoDetectCookieSupport=1)
http://www.nihpromis.org/about/overview?AspxAutoDetectCookieSupport=1

FACIT.org

- [Questionnaires](http://www.facit.org/FACITOrg/Questionnaires)
http://www.facit.org/FACITOrg/Questionnaires

Faculty Bio for Jennifer C. Obel, MD

Dr. Jennifer Obel is a board-certified medical oncologist who specializes in gastro-intestinal malignancies and palliative care. She earned her medical degree from Northwestern University's Feinberg School of Medicine, where she also completed an internship and residency in Internal Medicine and completed her hematology and oncology fellowship at the University of Chicago. Dr. Obel is an Assistant Clinical Professor, University of Chicago, prior to that she was an Assistant Clinical Professor of Medicine at Northwestern University.

Dr. Obel is the PI for the Palliative and Hospice design team of the Coleman Supportive Oncology Initiative, as well as community PI for a national study evaluating the role of early integrated palliative care. Prior to this role Dr. Obel led an oncology and outpatient quality improvement team, as part of the advance care planning initiative at NorthShore. As lead, Dr. Obel created and implemented goals-of-care workflow for newly diagnosed, stage IV cancer patients. She also developed the NorthShore advance care planning effort for end-stage congestive heart failure (CHF) patients. CHF patients also are confronted with decisions regarding resuscitative measures near end-of-life, typically during hospitalization. Data demonstrate only 12 percent of cardiologists engage their morbidly-ill, CHF patients in yearly discussions regarding EOL preferences and have difficulty identifying prospectively which of their CHF patients are at significant risk for death and who should be referred to early, integrated palliative care and hospice. Dr. Obel has developed internal medicine residency training programs for second and third year residents to enhance their ability to conduct in-depth advance care planning discussions. These curriculums are multi-modality, involving directly observed, video-taped encounters with patients actors as well as real-life encounters with patients. Lecturers, feedback sessions from trained experts, and online interactive course work are also involved.

Dr. Obel has worked successfully with numerous administrative leaders and department and division heads, along with informatics, quality improvement, spiritual care and nursing division members (over 50 different providers). She has successfully listened to multiple viewpoints, integrated those views into the project design, and navigated multiple challenges in order to implement new care processes for these significantly ill patients.

Faculty Bio for Christine B. Weldon

Christine Weldon is director and co-founder of the Center for Business Models in Healthcare (CBM-HC), an independent health services research organization focused on personalized care and precision medicine in oncology. Ms. Weldon's work follows a unique framework which involves collaborations with academic institutions, including Northwestern University and University of California San Francisco, medical centers, health care payers, product development companies and patient advocacies.

Christine has over twenty years of experience in business advisory, research and consulting services. Her expertise includes business model design, business visioning and planning, strategic decision-making support, facilitation of complex initiatives, business process optimization, organizational design and information management.

Ms. Weldon is an Adjunct Faculty member of the Northwestern University Feinberg School of Medicine and possesses an MBA from the Kellogg School of Management, Northwestern University and a BSBA from Drake University.

List of Ms. Weldon's publications available at:

<http://www.ncbi.nlm.nih.gov/sites/myncbi/1Bc7czwoYfu/bibliography/43309719/public/?sort=date&direction=ascending>

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- National Comprehensive Cancer Network®. NCCN Guidelines for Older Adult Oncology, Version 1.2018. Available at: https://www.nccn.org/professionals/physician_gls/pdf/senior.pdf
- National Comprehensive Cancer Network®. NCCN Guidelines for Palliative Care, Version 1.2018. Available at: http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf.
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Coleman Supportive Oncology Initiative

Distress Training Module

Topic: How to Address Patient Distress: Mild, Moderate and Severe, Using the Example of PHQ-4 Results

Presenters: James Gerhart, PhD, Suzanne M. Armato, MA; updated by Christine B. Weldon, MBA; Betty Roggenkamp, BA.

Version: 08282018

Learning Objectives

By the end of this module you should be able to:

- 1. Explain how to score and interpret distress screening, using the PHQ-4, in real time**
- 2. Identify the follow-up process for patients scoring with mild, moderate or severe depression and/or anxiety**
- 3. Employ urgent care needs for patients indicating immediate risk of harming them self or others**

Cancer Patient Distress

At some point during the course of a patient's cancer diagnosis and treatment, the patient may experience some level of distress in the form of anxiety and/or depression.

- Identifying distress is an essential component of overall patient care as identified by national leaders, including NCCN, ASCO and NCI.
- Assessing a cancer patient's level of distress is a critical first step to determining what resources and support they will need in order to alleviate stressors.
- Treating distress has been shown to result in more positive outcomes among cancer patients.

Cancer Patient Distress Screening: The PHQ-4

- **The PHQ-4 is a screening tool that measures anxiety and depression.**
 - **Anxiety questions to ask:**
 - Has the patient been feeling nervous, anxious or on edge?
 - Has the patient been unable to stop or control their worrying?
 - **Depression questions to ask:**
 - Has the patient had little interest or pleasure in doing things?
 - Has the patient been feeling down, depressed, or hopeless?
- **Can be self-administered by the patient or by a healthcare professional.**
- **Can quickly and accurately assess a patient in real time, giving the medical team key information to provide appropriate supportive oncology resources and interventions.**
- **Should be *administered more than once* – ideally should be given regularly throughout the treatment and care of a cancer patient.**

Scoring the PHQ-4

Over the last 14 days, how often have you been bothered by the following problems?²

Please mark one box per row

	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring: (0) (1) (2) (3)

Anxiety

Depression

≥ 3
OR
≥ 3

OR
≥ 6

Triggers a positive screen if patient scores:

- ≥ 3 for Anxiety questions
- ≥ 3 for Depression questions
- ≥ 6 for Total of all questions

The recommendation for anyone scoring 3 or higher is further screening for anxiety and/or depression.

Category scoring is based on total scores:

- Total Score = 0, 1, or 2
- Total Score = 3, 4, or 5
- or ≥ 3 on either Anxiety or Depression
- Total Score = 6, 7, or 8
- Total Score = 9, 10, 11, or 12

- Patient is presenting as *normal*
- Patient has a *mild* category score
- Patient has a *moderate* category score
- Patient has a *severe* category score

PHQ-4: Normal Category Score

A patient who scores a total of ≤ 2 on Anxiety or Depression questions, or a total score ≤ 5 , falls into the normal category.

Example:

Over the last 14 days, how often have you been bothered by the following problems?²

Please mark one box per row

	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to stop or control worrying	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Little interest or pleasure in doing things	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring: (0) (1) (2) (3)

Handwritten annotations: Brackets on the right side of the table indicate scores. The first row is bracketed and labeled "= 1". The second row is bracketed and labeled "= 1". A larger bracket on the right side of these two rows is labeled "= 2".

Next Steps for Normal Category Scores:

- Provide support and validation; encourage pleasant activity; relaxation
- Provide education about resources and supportive care options, if needed
- Inform patient about future routine screenings

Referral/Follow-Up Timing for Normal Category:

- Routine - only routine referrals are recommended at this level of scoring

PHQ-4: Mild Category Score

A patient who scores 3 - 5 on the total score falls into the mild category.

Example:

Over the last 14 days, how often have you been bothered by the following problems?²

Please mark one box per row

	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to stop or control worrying	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Little interest or pleasure in doing things	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring: (0) (1) (2) (3)

= 4

Next Steps for Mild Category Scores:

- Provide support and validation; have a mid-level provider assess for suicidal and/or homicidal ideation risk.
- A mid-level provider, in consult with the oncologist, further determines the appropriate referral for the patient.
- Inform patient about supportive care in the community/clinical setting.
- Inform patient of follow-up screenings.

Referral/Follow-Up Timing for Mild Category:

- Sub-acute - referral is recommended.
- Urgent - *immediate* referral to a physician or to the ER is recommended for those with suicide ideation risk.

PHQ-4: Moderate Category Score

A patient who scores a total ≥ 3 on the Anxiety or Depression Scale OR 6 - 8 on the total scale falls into the moderate category.

Example:

Over the last 14 days, how often have you been bothered by the following problems? ²

Please mark one box per row

	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not being able to stop or control worrying	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Little interest or pleasure in doing things	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring (0) (1) (2) (3)

} = 4
} = 6

Next Steps for Moderate Category Scores:

- Inform patient that symptoms are common reactions and can be managed.
- Complete comprehensive psychosocial assessment, identify concrete problems causing distress, and offer concrete supports; have a mid-level provider assess for suicidal and/or homicidal ideation risk.
- Recommend group therapy led by mental health clinician, behavioral activation, pharmacological treatment or structured self-help.

Referral/Follow-Up Timing for the Moderate Category:

- Sub-acute - referrals and assessments should occur within 1 - 3 days.
- Urgent - *immediate* referral to a physician or to the ER is recommended for those with suicide ideation risk.

PHQ-4: Severe Category Score

A patient who scores a total of 9 - 12 on the PHQ-4 falls into the severe category.

Example:

Over the last 14 days, how often have you been bothered by the following problems?²

Please mark one box per row

	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Scoring (0) (1) (2) (3)

= 11

Next Steps for Severe Category Scores:

- Inform the patient that their symptoms are common reactions and can be managed.
- Complete a comprehensive psychosocial assessment, identify concrete problems causing distress and offer concrete supports; have a mid-level provider assess for suicidal and/or homicidal ideation risk.
- The social worker in consult with the medical oncologist and/or mid-level provider, can determine the appropriate referral.
- Refer to psychologist for non-pharmacologic treatment such as cognitive behavioral therapy, interpersonal therapy, or other evidence-based treatment and/or consider pharmacology.

Referral / Follow-Up Timing for Severe Category:

- Urgent - referrals and assessments should occur the same day; patient should be seen by a physician or in the ER.

Talking about Suicide

Review your institution's protocol for suicide prevention prior to initiating screening.

- Patients will be more comfortable if your team is prepared.

Prevalence of Suicide

- Approximately 40,000 suicides occur each year.
- Depression and cancer are risk factors for suicide, as are older age, being non-Hispanic white and a prior history of suicide attempt.
- Worldwide, 9% of people will consider, attempt or complete suicide in their lifetime.

Asking about Suicide

- When mild to severe distress is indicated by a PHQ-4 screen, ask patients if they have had suicidal thoughts.
- Asking about suicide does not give someone the idea.
- Some professionals feel uncomfortable asking.
 - Being straightforward, kind and professional may ease your and your patient's distress.
 - Sample language to use: "Sometimes when my patients feel this way they also think about harming themselves or others, I wonder if you have been having thoughts like this?"

Maintaining Safety

- **If a patient endorses suicidal thoughts, respond with reflection and empathy.**

“It sounds like this has been an overwhelming time for you.”
- **Offer support.**
- **Additional screening by an onsite social worker, psychologist or physician is warranted as soon as possible.**
- **The patient may require further evaluation at an emergency room.**
- **1-800-273-TALK (8255) can be consulted by patients or healthcare professionals during a crisis.**

Summary of Points Covered

In this training module we addressed:

- **How to score and interpret a distress tool in real time, using the PHQ-4.**
- **How to follow up for patients scoring with mild, moderate or severe distress results.**
- **How to help patients who are indicating they are at imminent risk of harming self or others.**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network®

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Distress Management Version 2.2018](#)

http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

National Cancer Institute (NIH)

- [Coping with Cancer](#)

<http://www.cancer.gov/about-cancer/coping>

American Society of Clinical Oncology ASCO®

- [www.asco.org](#)

Association of Community Cancer Centers

- [Cancer Survivorship, Resources & Tools for the Multidisciplinary Team](#)

<http://www.accc-cancer.org/resources/cancerSurvivorship-Wellness.asp>

Faculty Bio for James Gerhart, PhD

Dr. Gerhart is an assistant professor and licensed clinical psychologist at the Rush Cancer Center. His research focuses on stress related to chronic illnesses including cancer.

Dr. Gerhart is particularly interested in the ways that family and professional caregivers respond when patients express their emotions about cancer. His current projects include the Coleman Supportive Oncology Initiative, and enhancing resilience among professional caregivers.

For additional information:

https://www.researchgate.net/profile/James_Gerhart

Faculty Bio for Suzanne M. Armato, MA

Suzanne Armato is the Executive Director of The Cancer Support Center, which provides comprehensive supportive psycho social services and wellness programs to anyone impacted by cancer, survivor or caregiver, at no cost. These services are offered throughout Chicago's Southland to more than 70 communities and in two locations.

The Center has strategic partnerships with several hospitals in the geographic area. Armato has more than twenty years in non-profit management and has a MA from The University of Chicago's School of Social Service Administration.

For additional information:

www.cancersupportcenter.org

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