

Distress as a Psychological Issue in Cancer Patients

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- I have no significant relationships to disclose

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Objectives

- Upon completion of this presentation each participant will be able to:
- Verbalize the definition of psychological distress.
- State the issues related to psychological distress across the disease trajectory.
- Discuss possible therapeutic interventions for psychological distress in cancer patients.

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To Keep You Current

- All studies discussed in this presentation have been published with the last two years.

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Psychological Distress is Not Depression Major Depressive Episode DSM-IV-TR ¹

- A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.
- (1) Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful).
 - (2) Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others).
 - (3) Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day.

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Psychological Distress is Not Depression Major Depressive Episode DSM-IV-TR ¹

- (4) Insomnia or hypersomnia nearly every day.
- (5) Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
- (6) Fatigue or loss of energy nearly every day.
- (7) Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
- (8) Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
- (9) Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

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Psychological Distress is Not Depression Major Depressive Episode DSM-IV-TR ¹

- B. The symptoms do not meet criteria for a Mixed Episode (also manic).
- C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
- E. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

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Psychological Distress is Not Anxiety

- State versus Trait Anxiety
- There are many type of anxiety disorders:
 - Acute Stress Disorder.
 - Agoraphobia (with or without a history of Panic Disorder).
 - Generalized Anxiety Disorder (GAD).
 - Obsessive-Compulsive Disorder (OCD).
 - Panic Disorder (with or without Agoraphobia).
 - Phobias (including Social Phobia).
 - Posttraumatic Stress Disorder (PTSD).

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What is Psychological Distress?

- "The unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person."²
- Manifestations of distress vary greatly across individuals.

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Antecedents of Psychological Distress

- Living, Conscious, Biopsychosocial Being.
- A Stressor.
- Perception that the Stressor is a Personal Threat.
- Loss of Control, Either Perceived or Actual.
- Ineffective Coping.

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Signs and Symptoms of Psychological Distress-How do we know it when we see it?

- Perceived by Inability to Cope Effectively.
 - Patient, family, caregiver (lay and/or professional) may notice this in our patients.
- Change in emotional status.
 - Something isn't "quite right."
 - Change from a more stable baseline.
- Discomfort.
 - Many manifestations- silence, irritability, tears, restlessness, anxiousness.
- Communication of discomfort.
 - Talking directly about a problem.
 - Yelling at family of staff.
 - Facial expressions.
 - Talking about a seemingly benign topic, when one can't swallow.
- Harm.
 - Wear and tear to self and to possibly others.

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Why is Psychological Distress Important?

- Distress as the 6th Vital Sign.
- Morality and Quality of Life (QOL) Implications:
 - History of psychological distress before allo-SCT had significant influence on early death in year one.³
 - Initial distress in breast cancer survivors "most potent predictive factor for long-term QOL."⁴

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Psychosocial Distress Assessment/Measurement Methods

- One Meta-analysis identified 48 different tools. Clinical Interview. ⁵
 - Hospital Anxiety and Depression Scale (HADS).*
 - Profile of Mood States (POMS).
 - Brief Symptom Inventory (BSI-18).
 - "Simple Help Question."
 - Distress Thermometer.

*Number 1 in meta-analysis

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Clinical Interview

- Bio-psychosocial model (Holistic):
 - Person and Disease - Multiple Levels of Expression:
 - Biological.
 - Psychological.
 - Social.
- Guidelines by the Distress Management Panel of the National Comprehensive Cancer Network. ⁶

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Clinical Interview

- Two Methods for Establishing Psychological Distress:
 - Interview Method.
 - Specific Tests (Instruments):
 - HADS.
 - Psychological Distress Inventory (PDI).
 - Brief Symptom Inventory (BSI).
 - Distress Thermometer.

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Clinical Interview

- Psychodiagnostic Interview:
 - Preliminary Meeting, Introduction.
 - Administration of Questionnaires:
 - Evaluation of Distress and Actual Needs.
 - Clinical Interview:
 - 15-20 Minutes Long.
 - Focus:
 - Experience of Illness.
 - Previous Psychopathology.
 - Personal, Family, Social Resources.

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Hospital Anxiety and Depression Scale (HADS) ⁷

- Used across the entire trajectory in the meta analysis.
- Assesses for Anxiety and Depression.
- Obtained for a fee from National Foundations for Education Resources, UK.

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Profile of Mood States (POMS) ^{8,9}

- POMS-SF:
 - 37 Items, 10 Minutes.
- POMS Standard:
 - 65 Items, 20 Minutes.
- Both Instruments Measure:
 - Tension-Anxiety.
 - Depression-Dejection.
 - Anger-Hostility.
 - Vigor-Activity.
 - Fatigue-Inertia.
 - Confusion-Bewilderment.
- Both can be re-administered on a weekly basis.
- Obtained for a fee from MHS Psychological Assessments and Services – often a lengthy process.

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Distress at Pre-Diagnosis ¹²

- **Methods (cont'd):**
 - State-Trait Anxiety Inventory (STAI).
 - Impact of Events Scale (IES).
 - Breast cancer-risk perception.
- **Findings:**
 - Low to moderate anxiety in both groups.
 - Low cancer-specific distress in both groups.
 - Abnormal surveillance result associated with higher STAI-State anxiety and IES-Intrusion scores
 - Personal breast cancer history and higher risk perception associated with higher psychological distress at T1 and T2.

Distress at Pre-Diagnosis ¹³

- **Objectives:**
 - To assess the psychological burden (state anxiety, cancer worry, psychosocial burden) of testing positive for high-risk HPV in Chinese women with atypical squamous cells of undetermined significance.
- **Methods:**
 - Prospective observational study. Structured telephone interviews at and 6 months following dx. (N=299, n=142 HPV- : n=157 HPV+)
 - STAI-6.
 - Adaptation of the Breast Cancer Worry Scale.
 - HVP Impact Profile (7 subscales).

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Distress at Pre-Diagnosis ¹³

- **Findings:**
 - Pre-diagnosis: No difference in cancer knowledge or intimate relationship satisfaction.
 - Diagnosis: HPV+ significantly higher in all outcome categories:
 - Higher perceived risk of cancer:
 - Increased cancer knowledge.
 - Six months: HPV+ psychosocial burden significantly different.

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Distress at Pre-Diagnosis ¹⁴

- **Objectives:**
 - To evaluate psychological distress in women undergoing screening for familial ovarian cancer .
- **Methods:**
 - Cross-sectional; N = 1979.
 - HADS.
 - IPES.
 - Illness Perceptions Questionnaire.

Distress at Pre-Diagnosis ¹⁴

- **Findings:**
 - 2.8% moderate-high levels of depression .
 - 17% moderate-high levels of anxiety.
 - 27.3% high levels of ovarian cancer specific distress.
 - Anxiety and negative emotional representations of ovarian cancer risk associated with greater ovarian cancer-specific distress.

Clinical Implications: Pre-Diagnosis

- Patients who are at risk are distressed.
- This may be cancer specific or more general stress.
- Distress may not dissipate over time.
- Families could also be distressed.
- Counseling may be needed.

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Distress at Diagnosis ¹⁵

- Objectives:
 - To determine how age and psychological characteristics assessed prior to diagnosis could predict psychological distress in outpatients immediately after disclosure of breast cancer diagnosis.
- Methods:
 - State-Trait Anxiety Inventory.
 - Courtauld Emotional Control Scale.
 - Life Experiences Survey.
 - POMS.
- Findings:
 - Trait anxiety predicted distress after diagnosis (N=136; n=38 breast cancer; n=98 benign).

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Distress at Diagnosis ¹⁶

- Objectives:
 - To study the level of cancer related distress and associated variables in patients recently diagnosed with testicular cancer.
- Methods:
 - Cross-sectional study of psychological and cognitive functioning (N=135).
 - Impact of Events Scale.
 - HADS
 - Positive and Negative Affect Scale.
 - Neuropsychiatric battery of tests.

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Distress at Diagnosis ¹⁶

- Findings:
 - Clinically significant cancer related distress in 24%:
 - Neuroticism, daily smoking, hazardous alcohol use contributed.
 - Three neuropsych domains were associated with at least one distress measure:
 - Attention.
 - Working Memory.
 - Executive Functions.

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Clinical Implications - Diagnosis

- Chronically anxious and neurotic individuals may be more at risk for psychological distress.
- These underlying personality issues may not respond to therapy.
- Alterations in neurocognitive function may contribute to psychological distress.
- Baseline psychological screening may help identify high risk patients.

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Distress During Treatment ¹⁷

- Objectives:
 - To describe the clinical experience of a 12-week pilot study of "distress screening" for newly admitted oncology inpatients and its outcomes.
- Methods:
 - Program evaluation of pilot implemented distress screening protocol.
 - Distress Thermometer.
 - BSI-18.
 - Staff interview.

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Distress During Treatment ¹⁷

- Findings:
 - 115/168 admitted patients completed the two instruments at admission. DT score of 5 triggered referrals as Global Severity Index Score of at least 63. Social workers then saw patients and recommended further treatment.
 - 51% met at least one of the criteria.
 - Statistically significant increase in psych referral from pre-pilot baseline.
 - 94% of staff wanted the program continued:
 - Helped identify distress.
 - Nurses wanted a larger role.

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Distress During Treatment ¹⁸

- Objectives:
 - To examine associations between global distress and three types of cancer support communication (self-disclosure, perceived partner disclosure, protective buffering) among patients with head and neck or lung cancer and their families (average 15 months since initial diagnosis).
- Methods:
 - Cross-sectional design using the Intimacy Model which suggests that relationship intimacy mediates couples cancer support communication and psychological distress.
 - Cancer Rehabilitation Evaluation System (physical disability).
 - Three item perceived partner-disclosure.
 - Three item self disclosure.
 - Twenty item protective buffering scale.
 - Global Relationship Intimacy Scale.
 - BSI-18.

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Distress During Treatment ¹⁸

- Findings:
 - Global and cancer-specific intimacy fully mediated self and perceived partner disclosure and cancer specific intimacy.
 - Global intimacy partially mediated protective buffering and distress.
 - Lower levels of distress were found as a function of global and cancer specific intimacy (but stronger for partners than patients).

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Distress During Treatment ¹⁹

- Objectives:
 - To compare depression, anxiety, body image, sleep disturbances, and quality of life in prostate cancer patients undergoing androgen-deprivation therapy (ADT), as opposed to patients in follow-up alone.
- Methods:
 - Cross-sectional, prostate cancer clinic; N = 103; 49 (47.6%) receiving adjuvant ADT and 54 (52.4%) in follow-up.

Distress During Treatment ¹⁹

- Methods (cont'd):
 - Sociodemographic data .
 - HADS.
 - Functional Assessment of Cancer Therapy – Prostate.
 - Body Image Scale.
 - Pittsburgh Sleep Quality Index.

Distress During Treatment ¹⁹

- Objectives:
 - To evaluate efficacy of an interactive self-help workbook in reducing distress and breast cancer patients.
- Methods:
 - Randomized Clinical Trial (N=49; 25 exp., 24 cont.) Measured at Baseline, 3, & 6 months.
 - Depression Anxiety Stress Scales-21 items.
 - Post Traumatic Stress Diagnostic Scale.

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Distress During Treatment ¹⁹

- Findings:
 - Patients receiving ADT had more depression ($p = .002$), worse body image ($p = .001$); worse quality of life ($p = .0001$), and worse sleep quality ($p = .04$).
 - No differences in anxiety.
 - ADT more depressed.
 - Total BSI greater for ADT (worse).
 - No differences in sleep.
 - Total FACT-P lower in ADT –only emotional and cancer QOL subscales were similar.

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Distress During Treatment ²⁰

- Objectives:
 - To investigate the safety and efficacy of fluvoxamine therapy in gynecological cancer patients with post-diagnosis distress.
- Methods:
 - Quasi-experimental, pre-treatment-post treatment design.
 - 8 weeks of medication
 - 118 approached; 10 consented and completed the study.
 - Measures at 6 and 8 weeks.
 - HADS.

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Distress During Treatment ²⁰

- Findings:
 - Overall- HADs improved at both time points.
 - No adverse events.

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Clinical Implications - During Treatment

- Assessment of distress inpatients increase per referral and is acceptable to staff.
- Communication with partners is important and impacts the level of distress.
- Patients may not want medication, thus other treatment modalities may need to be explored.

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Distress During Treatment and Transition ²¹

- Objectives:
 - To determine if psychological outcomes of inpatient surgical cancer patients can be improved overtime by an inpatient psycho-support program.
- Method:
 - Randomized Clinical Trial (N=131, 48 males, 83 females). Assessed pre-treatment, stratified to low versus high risk groups, then randomized to standard care or psycho-support therapy within these two groups. Measured at discharge and 12 months later.
 - HADS

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Distress During Treatment and Transition ²¹

- Findings:
 - 77% were high risk pretreatment.

	Discharge		12 Months	
	Depression	Anxiety	Depression	Anxiety
HRE	*↓	*↓	↓	*↓
HRC	↓	↓	*↓	*↓
LRE	↑	↓	↑	↑
LRC	↑	↑	↑	↑

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Distress During Transition ²²

- Objectives:
 - To develop and test a supportive care program for people with potentially curative colorectal cancer.
- Methods:
 - Pre-intervention/post-intervention evaluation of 8 patients. Intervention consisted of DVD, booklets, individualized care plan, face-to-face nurse end-of treatment session-3 follow up nurse lead phone calls. Baseline-nurse lead consult-final phone call.
 - BSI-18.
 - Distress Thermometer.

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Distress During Transition ²²

Table 2 • Distress in Cancer Survivors

	Mean	Range	No. (%) of Likely Clinical Cases
Baseline (n = 10)			
Total BSI-18	10	0-24	3 (30)
Distress thermometer (0-10)	1	0-4	1 (10)
Follow-up (n = 8)			
Total BSI-18	8	1-16	3 (38)
Distress thermometer (0-10)	2	0-6	2 (25)

Abbreviation: BSI-18, 18-item Brief Symptom Inventory.

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Distress During Transition ²³

■ Objectives:

- To examine factors associated with increased emotional distress in head and neck cancer patients before and after treatment.

■ Methods:

- Longitudinal, at admission before treatment and 6 months after admission; n = 113 head and neck cancer; n = 1690 other cancers.
- HADS.
- Sociodemographic and Clinical Variables.
- Functional Assessment of Cancer Therapy (FACT) Social Support subscale.

Distress During Transition ²³

■ Findings:

- Distress at admission: 61% HN; 51% other cancers.
- Distress at 6 months: 68% HNC; 44% other cancers (OR 2.69; CI 1.19-6.07; p = .01).
- Recurrent disease, radiation, household income, and perceived social support associated with emotional distress.
- Patients without social support were 3.31 times more likely to be emotionally distressed.

Distress During Transition ²⁴

■ Objectives:

- To determine if higher levels of self-efficacy and perceived preparedness for end-of-treatment are associated with better mood and lower health related distress.

■ Methods:

- Cross-sectional study of 440 women completing treatment for early stage breast cancer
- Instruments:

Distress During Transition ²⁴

■ Findings:

- Women having chemotherapy who were <50 years old higher mood disturbance and health-related distress.
- Self-efficacy preparedness, younger ages predicted 36% variance in mood disturbance scores.
- Self-efficacy and age predicted 26% variance in health related distress.

Clinical Implications - Transition

- Non-pharmaceutical—Psychoeducational support may reduce distress associated with transition.
- Self-efficacy and perceived preparedness are important variables for successful transition after treatment.

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Distress During Survivorship ²⁵

- Objectives:
 - To examine the extent to which illness perceptions and coping strategies are related to levels of psychological distress among esophageal cancer survivors.
- Methods:
 - Cross-sectional, mailed questionnaire (N = 484).
 - Illness Perception Questionnaire-Revised.
 - Cancer Coping Questionnaire.
 - HADS.

Distress During Survivorship ²⁵

- Findings:
 - 36% probable anxiety.
 - 24% probable depression.
 - Younger patients and those without a caregiver more likely to be anxious.
 - Patients with other illnesses more likely to be depressed.
 - Beliefs about esophageal cancer and illness perceptions affected psychological adjustment.
 - Diversionary coping associated with increased anxiety.

Distress During Survivorship ²⁶

- Objectives:
 - To examine the prevalence of depressive symptoms and mental well-being in adult, long-term (20 yrs.) survivors of childhood acute lymphoblastic leukemia as compared to healthy controls.
- Methods:
 - Beck Depression Inventory 2-Depressive Symptoms.
 - General Health Questionnaire-Mental Distress.

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Distress During Survivorship ²⁶

- Findings:
 - ALL survivors significantly less depressed:
 - No differences based on sex between ALL.
 - Female ALL survivors lower BDI Scores.
 - No difference in overall mental distress.

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Clinical Implications - Survivorship

- Younger survivors of adult cancer are more distressed.
- Adult survivors of childhood cancer are less depressed than healthy people.
- Caregiver support and social support can reduce distress.

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Distress During End-of-Life ²⁷

- Objective:
 - To explore the feasibility, benefits, and barriers to exercise intervention in advanced stage lung cancer patients.
- Methods:
 - 4-week combination of hospital-based group exercise (warm-up, resistance, relaxation) and unsupervised home gait training, respiration, and relaxation training). N=15. One focus group.

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Distress During End-of-Life ²⁷

- No previous history of exercise.
- 76% adherence to group exercise-no compliance with home-based work.
- Strength training viewed as improving well-being.
- Relaxation helpful.
- Exercising with others having similar problems/symptoms was viewed a very important.

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Distress During End-of-Life ²⁸

- Objective: Hypothesis testing comparing palliative care patients and caregivers to age matched controls. Caregivers and palliative care patients:
 - A. Have higher psychological distress.
 - B. More rumination on existing concerns.
- Methods:
 - Cross-sectional design of (pcp,n=36; cg; n=26; amc, n=30) in the United Kingdom:
 - Beck Fast Screen Inventory.
 - General Anxiety Disorder.
 - Response Style Questionnaire Ruminative Subscale and Semi-Structured Interview.

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Distress During End-of-Life ²⁸

- Findings:
 - Have higher psychological distress.
 - More rumination on existing concerns.
 - Rumination correlated with anxiety, depression, and frequency of existential concerns (influences distress).
 - Frequency of existential concerns correlated with anxiety and depression

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Distress During End-of-Life ²⁹

- Objective:
 - To assess the association of spiritual well-being (SWB) with depression, anxiety, distressing symptoms, and QOL.
- Methods:
 - Cross-sectional design of 50 Indian palliative care patients (gynecological, lung, breast stomach, and "others").
 - HADS.
 - VAS and M. D. Anderson Symptom Inventory.
 - FACT-G and FACT-Pal.

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Distress During End-of-Life ²⁹

- Findings:
 - SWB negatively correlated with Depression and Anxiety.
 - SWB negatively correlated with:
 - Fatigue.
 - Symptom Distress.
 - Memory Disturbance.
 - Appetite Loss.
 - Drowsiness.
 - Dry Mouth.
 - Sadness.
 - SWB positively correlated with all subscale of the QOL instruments.

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Distress During End-of-Life ³⁰

- Objective:
 - To investigate anxiety in terminally ill cancer patients.
- Methods:
 - N = 194; mixed cancer diagnoses; receiving inpatient palliative care or outpatient care at tertiary cancer center.
 - HADS
 - Beck Hopelessness Scale.
 - Schedule of Attitudes toward a Hastened Death.
 - Duke-UNC Functional Social Support Questionnaire.

Distress During End-of-Life ³⁰

- Findings:
 - 18.6% HADS score 8 – 10.
 - 12.4% HADS score > 11.
 - Presence of worrying thoughts most strongly endorsed item.
 - Anxiety positively correlated with depression (0.54), hopelessness (0.54), and desire for hastened death (0.53); negatively correlated with social support (-0.27).

Distress During End-of-Life ³⁰

- Findings:
 - Women reported significantly higher levels of anxiety than men.
 - Belief in an afterlife and levels of anxiety:
 - No belief in an afterlife had lowest level of anxiety.
 - Followed by definite belief in an afterlife.
 - Unsure or “somewhat” belief in an afterlife significantly higher levels of anxiety.

Clinical Implications - End-of-Life

- Spirituality is important.
- No belief or strong belief in afterlife are both less distress than “uncertain” individuals.
- Social support is helpful.
- Patients who are very ill will participate in activities that they view as helpful, but need direct supervision.
- Relaxation techniques may be of benefit at end-of-life.
- Being with similarly ill persons is viewed as helpful.

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Summary

- Psychological distress is an issue across the entire cancer trajectory.
- Psychological distress often operationalized as depression and/or anxiety – problematic.
- Studies presented reflect:
 - Presence of this distress.
 - Attempts across the trajectory to manage the distress (although somewhat limited) utilizing different treatment modalities and providers.
- Implies entire cancer team is responsible for identifying and managing psychological distress.
 - One study suggests we agree with this.³¹

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Summary

- Although a “hot topic,” Randomized Clinical Trials testing interventions are not prevalent.
- Although focus has been primarily on patients, caregivers are also distressed.
- So what are we to do?

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Role of Oncologist in Managing Psychological Distress ³²

- Recognize the problem.
- Recognize your role as the “psychoeducator.”
- Screening does not have to be complex:
 - Are you depressed/distressed?
 - Are you interested in supportive therapy?
- Family meetings.
- Acknowledge psychotherapy and pharmacological therapy.
- Refer for treatment.

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Role of Oncologist in Managing Psychological Distress ³²

- Conduct a Self-Assessment:
 - Are you comfortable and competent enough to assess emotional distress?
 - Are your communication skills adequate?
 - If not then go to training, seek mentoring.

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Role for Oncology Nurses ³³

- Nurses can and should play a primary role in initial screening for psychological distress.
- Organizations should support this role.
- Distress Thermometer.
- Treat psychological distress as the 6th vital sign.

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Key Points

- Multidisciplinary approach to assessment, screening, diagnosis, and treatment is needed.
- Health symptoms approach is also indicated:
 - Policies and procedures – Distress as 6th vital sign.
 - Automated electronic assessment/screening triggering automatic referral.

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