DISTRESS SCREENING: THE 6TH VITAL SIGN IN CANCER CARE

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ORIGINS OF DISTRESS SCREENING

- Psychosocial care is highly valued by oncology patients and families
  - Historically seen as separate from routine medical care
- In 1997, NCCN convened a multidisciplinary panel to look at this issue
  - Recommendation: Use the universal pain scale as a model for capturing psychosocial distress

DISTRESS DEFINITION

"An unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with people's ability to cope"
MAKING THE CASE FOR DISTRESS SCREENING

- Prevalence of distress in oncology patients has been estimated at >30% in various studies

- Distress is underdiagnosed
  - 29% of the patients with scores indicating distress were correctly identified by MDs. Fallowfield et al.
  - 39% of distressed patients were correctly identified by MDs and only 40% by nurses. Keller et al.

- Distress is undertreated
  - In Keller’s study, only 31% of patients with high distress were referred for psychosocial care
  - 12% of breast or gyn cancer patients with major depression received medication and only 1% saw a counselor or participated in a support group. Ell et al.

FURTHER REASONS FOR ASSESSING DISTRESS:

- In various studies, distress has been linked to:
  - Worsening quality of life
  - Higher levels of pain
  - Increased family burden
  - Reduced adherence to treatment
  - Shorter survival expectancy (when related to hopelessness)
  - Risk of suicide (when related to hopelessness)

TOOLS FOR MEASURING DISTRESS

- Many options available
  - NCCN Distress thermometer
  - Beck Depression Inventory
  - Rotterdam Symptom Checklist
  - etc.

- Validity
  - Pooled analysis of 38 studies of ultra-short screening tools for depression (13 using the NCCN DT)
    - Sensitivity: 78.4%
    - Specificity: 66.8%
    - Positive Predictive Value: 34.2%
    - Negative Predictive Value: 13.4%
### MANAGEMENT OF EXPECTED DISTRESS SYMPTOMS

- Acknowledge distress
- Clarify diagnosis, treatment options and side effects
- Educate patients that points of transition may bring increased vulnerability to distress
- Build trust
- Ensure continuity of care
- Mobilize resources
- Consider medications to manage symptoms
- Support groups and/or individual counseling
- Refer for family support and counseling
- Relaxation, meditation, creative therapies
- Spiritual support
- Promote exercise

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#### NCCN Distress Thermometer for Patients

**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. Be sure to check YES or NO for each.

<table>
<thead>
<tr>
<th>Extensive Distress</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>No Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>

#### NCCN Guidelines Version 3.2015

**Distress Management**

- **EVIDENCE OF EVALUATION AND TREATMENT PROCESS**
  - **EVALUATION**
    - Clinical assessment
      - Identify patients at risk
      - Consider psychosocial issues
      - Assess for psychological distress
    - Screening tools
      - Distress Thermometer
      - Other validated tools
    - Determine need for intervention
  - **TREATMENT**
    - Interventions
      - Psychological
        - Individual counseling
        - Group counseling
      - Psychological
        - Pharmacological
        - Referral to specialty services
      - Other interventions
        - Medications
        - Support groups
        - Relaxation, meditation, exercise
      - Spiritual support
    - Follow-up and communication
      - With patient and caregiver/family

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*Refer to NCCN Guidelines for the latest guidance on Distress Management.*
COMMUNICATION AND REFERRALS

- Consider automatic referral to social work or other service for distress score ≥ 4

DISTRESS GUIDANCE

- CoC Standard
  - Develop and implement a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care

- NCCN Standards of Care
  - 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 distress
  - Interdisciplinary institutional committees should be formed to implement standards for distress management
  - Patients, families, and treatment teams should be informed that distress management is an integral part of total medical care

IMPLEMENTING DISTRESS SCREENING

- Interdisciplinary planning is necessary
- Partners: nurses, care providers, chaplains, social work, patient advocates, psychiatry/psychology
- Select tool(s) to screen for distress
- Define a “pivotal medical visit” at which time the screening occurs
- Define a process for how information is obtained
- Create a process for assessment and referral procedures when “moderate” or “severe” distress is found
- These procedures should “identify and examine the psychological, behavioral, and social problems of patients that interfere with the ability to participate fully in their health care and manage their illness and its consequences”
- Plan for documentation in the patient medical record
UTILIZING DISTRESS SCREENING

- Distress screening generates a large amount of data
- Consider capturing in EMR to allow later extraction
- Evaluating these data may help to:
  - Describe your patient population
  - Identify unmet needs
  - Strengthen the case for new interventions
  - Identify groups at highest risk for distress
  - Measure the impact of an intervention

ARE CANCER SURVIVORS DISTRESSED?

![Bar chart showing percentage of survivorship patients by distress score]

HOW DOES DISTRESS AT THE SURVIVORSHIP VISIT COMPARE TO INITIAL DISTRESS?

![Line graph comparing distress scores at initial visit and survivorship clinic visit]
DOES TRAVELING FOR CANCER CARE INCREASE DISTRESS FOR VETERANS WITH H&N CANCER?

METHODS

- Analysis restricted to Veterans with H&N cancer referred for radiation or chemoradiation
- Distance to VA calculated by zip code
- Distance > 50 miles defined as “traveling”
- Distress thermometer completed per protocol
  - Score ≥ 7 defined as “significant distress”
- Logistic regression used to control for possible effects of cancer stage, age category, treatment plan

DEMOGRAPHICS

<table>
<thead>
<tr>
<th></th>
<th>&lt; 50 Miles</th>
<th>&gt; 50 Miles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>32</td>
<td>28</td>
</tr>
<tr>
<td>White race</td>
<td>23 (72)</td>
<td>23 (82)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 60</td>
<td>4 (13)</td>
<td>6 (21)</td>
</tr>
<tr>
<td>60—69</td>
<td>16 (50)</td>
<td>19 (68)</td>
</tr>
<tr>
<td>70+</td>
<td>12 (38)</td>
<td>8 (11)</td>
</tr>
<tr>
<td>Treatment plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemoradiation</td>
<td>14 (44)</td>
<td>18 (64)</td>
</tr>
<tr>
<td>Radiation alone</td>
<td>18 (58)</td>
<td>10 (36)</td>
</tr>
<tr>
<td>Cancer stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I or II</td>
<td>10 (31)</td>
<td>4 (14)</td>
</tr>
<tr>
<td>III</td>
<td>10 (31)</td>
<td>4 (14)</td>
</tr>
<tr>
<td>IV</td>
<td>12 (38)</td>
<td>20 (71)</td>
</tr>
<tr>
<td>Average distress score</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
**UNADJUSTED AND ADJUSTED ODDS RATIOS (P VALUE) OF SIGNIFICANT DISTRESS BY RISK FACTORS**

<table>
<thead>
<tr>
<th></th>
<th>Unadjusted</th>
<th>Adjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 50 miles</td>
<td>1.68 (0.01)</td>
<td>1.64 (0.02)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60–69</td>
<td>-0.78 (0.28)</td>
<td>-0.56 (0.48)</td>
</tr>
<tr>
<td>70 +</td>
<td>-1.4 (0.125)</td>
<td>-0.37 (0.72)</td>
</tr>
<tr>
<td>Treatment plan:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation alone</td>
<td>-0.91 (0.12)</td>
<td>-0.40 (0.55)</td>
</tr>
<tr>
<td>Cancer stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>15.37 (0.99)</td>
<td>15.03 (0.99)</td>
</tr>
<tr>
<td>IV</td>
<td>16.98 (0.99)</td>
<td>16.69 (0.99)</td>
</tr>
<tr>
<td>V</td>
<td>17.39 (0.99)</td>
<td>16.31 (0.99)</td>
</tr>
</tbody>
</table>

**COMMON SOURCES OF DISTRESS AMONG VETERANS WITH HEAD AND NECK CANCER**

- Mouth sores
- Treatment decisions
- Memory/concentration
- Nose dry/congested
- Sadness
- Depression
- Fears
- Insurance/financial
- Transportation
- Fatigue
- Worry
- Sleep
- Eating
- Feeling swollen
- Nervousness
- Pain

**LIMITATIONS AND IMPLICATIONS**

- Limited analysis (n=60)
- Administered at 1 time point, prior to start of treatment
- Veterans with H&N cancer traveling > 50 miles for cancer care are more likely to report significant distress
- Further investigation needed to identify ways to address distress prior to first trip
- Veterans traveling for prostate cancer care do not have significant levels of distress
What are the barriers to implementing distress screening at your institution?

What questions would you like to explore using distress data?