You've Screened for Distress, Now What?

OncoLink's Distress Screening Response Tools (DSRT): Emphasizing Patient Engagement, Education and Empowerment

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Learning Objectives

• Understand the educational needs of patients who have been screened for distress and resources available to meet these needs.
• Demonstrate knowledge of patient education materials available through the DSRT and how to access these for patients, caregivers and healthcare providers.
• Integrate patient education, empowerment, and engagement into the delivery of psychosocial oncology care.

What is OncoLink?

• First cancer information website on the Internet.
• Founded in 1994, by a Penn radiation oncologist.
• Content written by physicians, nurses, dieticians, social workers, spiritual care providers, integrative oncology practitioners and cancer survivors.
• All content via www.oncolink.org is available for free; no registration is required.
• Material is written at various levels; the “higher level” or “deeper” content is not segregated for healthcare professionals only.
• Materials available for patients, families, healthcare providers and the public.
• Users: 65% US, 10% PA/NJ/DE, 1.5% Philadelphia
• World wide presence: top international audiences from UK, Canada, Australia and India
What is the DSRT?

• The DSRT is OncoLink’s Distress Screening Response Tools.
• The DSRT is a first of its kind resource for patients, caregivers and healthcare professionals to provide educational materials that focus on treatment and interventions for the practical, emotional, spiritual and physical domains of cancer related distress included in the NCCN Distress Thermometer and Problem List.
• The DSRT is for ALL screened patients; but especially helpful to those who may not screen “high enough” to receive further consultation or intervention for their cancer related distress, but still have educational needs for managing problems.

Why the DSRT?

• The data about distress is DISTRESSING
  • An estimated 35% of cancer patients screened report some level of distress (Zabora, et al., 2008).
  • 28% of respondents to the National Survey of Households Affected by Cancer reported their doctor did not address needs beyond their direct medical care.
  • Physicians tend to underemphasize cancer patients’ psychosocial distress (Fallowfield et al., 2002, Keller et al., 2006, Hockenberry et al., 2006).
• 1/3 of oncologists report they do not routinely address psychosocial issues/challenges or distress.

• Something is missing
  • Screening for distress is only PART of the process; limited recommendations for distress management.
  • Screening does not provide mechanisms to influence/change behaviors, assess coping mechanisms or provide coping resources.
  • Screening does not emphasize impact of patient education and self management on overall distress management.

REVIEW OF LITERATURE
IOM Report, *Cancer Care for the Whole Patient*, 2008

- “Patient education and advocacy organizations should educate patients with cancer and their family caregivers to expect, and request when necessary, cancer care that meets the standard for psychosocial care. These organizations should also continue their work on strengthening the patient side of the patient–provider partnership. The goals should be to enable patients to participate actively in their care by providing tools and training in how to obtain information, make decisions, solve problems, and communicate more effectively with their health care providers (pp. 237–238).”

Recommendations by the IOM

- Establish a standard of care for the provision of appropriate psychosocial health services.
- Healthcare providers should ensure that all cancer patients have access to quality psychosocial care.
- Increased patient and family education about the psychosocial impact of cancer.
- Engage payers in supporting the provision of psychosocial care as integral to cancer care.

What is Distress?

- Distress is defined 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.”
  - ASCO Standard of Care for Distress Management

- NCCN Standard of Care for Distress Management

- ASCO Standard of Care for Distress Management

- NCCN Standard of Care for Distress Management
NCCN Distress Management Guidelines, V 2.2014

- Implements standard of care for management of distress
  - 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.
  - 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 empower health care professionals and certified chaplains to have the knowledge and skills to assess and manage distress.
  - Licensed mental health professionals and certified chaplains with experience 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.
  - Patients, families, and treatment teams should be informed that management of distress is an integral part of 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 projects.

CoC Distress Screening Standard

STANDARD 3.4: Psychosocial Distress Screening

The cancer treatment and care plan includes a distress screening process, and a written plan is developed and implemented to provide psychosocial support and counseling to patients, families, and caregivers.

DISTINCTIONS AND REQUIREMENTS

Cancer is a complex disease process that affects patients as a whole. Therefore, psychological, social, financial, and spiritual concerns of patients can affect the course of the disease and treatment plan. The Distress Screening Standard of the Commission on Cancer (CoC) emphasizes the importance of recognizing distress in the context of the patient's overall health. Distress screening is part of the comprehensive assessment of patients receiving cancer care, and the results are used to guide the development of a comprehensive plan for the management of distress.

CoC DISTRESS SCREENING STANDARD

- Provide written guidelines for conducting distress screening and documentation.
- Use a validated distress screening tool that is appropriate for the patient population.
- Ensure that all providers are trained in the use of the screening tool.
- Provide follow-up and referral to appropriate services based on the screening results.
- Monitor and evaluate the implementation of the distress screening program.

Theory of Symptom Management  
Hoffman, 2013

- "Information is crucial to promote a sense of control, decrease emotional distress, support effective self management and eliminate disruptions of daily activities (pp. E12)."
- Distress as a symptom
  - "perceived warnings of threats to health and the subjective experience of the person (pp. E13)."
- Symptom self management
  - "a dynamic, self directed process of implementing behaviors that recognize, prevent, relieve or decrease the timing (frequency, duration, occurrence), intensity, distress, concurrence and unpleasant quality from symptoms to achieve optimal performance outcomes (pp. E12)."
- Self management "conveys a message of control, empowerment and confidence... (pp. E18)."

Self Management  
Lorig and Holman, 2003

- Represents a combination of medical management, education and "maintaining, changing, and creating new meaningful behaviors or life roles (Lorig and Holman, 2003, pp. 1)."
  - Five core self management skills:
    - Problem solving
    - Decision making
    - Resource utilization
    - Forming partnership between patient and provider(s)
    - Taking action (2-3)
  - Problem based:
    - Distress as a problem; self management as a intervention.
  - Screening helps us identify problems; the DSRT provides self management techniques for intervention based on problems.
  - Asking patients to take an ACTIVE role in the management of their distress.

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Patient Centered Care

- "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions (IOM, 2011)."
- "Patients are each very unique biological, social, psychological, economic, ethnic and spiritual beings... PATIENT CENTERED CARE will also provide help with achieving the best individual patient outcome through a team approach (patientcenteredcare.net)."
- Use of the DSRT to respond to a patient's individual identified needs is a model of patient centered distress management.

Patient Centered Care

- In a patient centered collaborative model
  - The patient is an active participant in discussion.
  - The patient is a partner in treatment decisions.
  - The patient and healthcare team collaborate on best approaches and plans.
  - Care centers around the patient's quality of life.
  - Healthcare team actively engages in conversation, but listens actively and is in tune with the needs of the patient.
  - Patient is more likely to be adherent as treatment plan includes and accommodates the patient's values, culture, thoughts and beliefs.

How does distress screening and management fit into this model?

A Distress Screening and Management Model
DEVELOPMENT AND DESIGN OF THE DSRT

How Did We Design the DSRT?

• Based on "problem list" of NCCN Distress Thermometer.
• Expanded to include educational content on other topics identified in clinical practice
  • Disability
  • FMLA
  • Navigating insurance
  • Recurrence
  • Advocacy
  • Survivorship
  • Advanced care planning
  • Caregiving
  • Home care, infusion and durable medical equipment
  • Specialty pharmacies

What Does the DSRT Include?

• Tips in a minute sheets
  • Patient centered education materials to promote patient empowerment and self management of cancer related distress.
  • Educational handouts for a variety of psychosocial topics that can be used to address concerns identified in distress screening of cancer patients.
• Video education modules
  • A series of short educational videos addressing common concerns during cancer treatment.
• Webinars
  • Focus on Spirituality
  • Spotlight on Cancer Caregivers
  • Spotlight on Nutrition: Using Food to Help Manage Symptoms
Application to Other Screening Tools

• PHQ 4/9
• Brief Symptom Inventory-18
• Hospital Anxiety and Depression Scale (HADS)
• Edmonton Symptom Assessment System (ESAS)
• Canadian Problem Checklist
• Psycho-oncology Screening Tool (POST)
• Functional Assessment of Cancer-General (FACT-G)
• Cancer Support Source
• City of Hope Support Screen

FAQ's

• Why the DSRT?
  • There is an expansive collection of literature research (mostly) about distress screening, but we found VERY LITTLE about what to do for managing distress (aside from a much debated cut-off point).
  • The DSRT focuses on patient empowerment and is patient centered source of educational, self-management materials.
  • How do I use the DSRT with my patients and their caregivers?
  • www.oncolink.org

• Is there a cost to access the DSRT?
  • All content included in the DSRT is available free of charge to patients, caregivers and healthcare providers.

• Does the DSRT interact with the EMR for documentation of patient education?
  • No. The DSRT is not a screening tool. The DSRT provides educational materials for responding to distress screening and distress management.

• Does the DSRT meet Commission on Cancer guidelines for distress screening?
  • No. The DSRT is not a screening tool.

Goals of the DSRT

- Decrease levels of distress through patient education.
- Increase accessibility of self-management tools.
- Increase ability to manage distress symptoms and ask for help.
- Increase quality of life.
- Improve adherence to treatment plan.
- Earlier intervention to address problems that may impact cancer treatment and survivorship.

Next Steps

- Study metrics of page views.
- Partner with treatment sites for more in-depth study of DSRT effectiveness and impact on patient education and quality of life.
- Expand content to include more video education modules and healthcare professional education regarding self-management and use of the DSRT.
- Gather feedback from users to include other important areas for self-management teaching that are occurring in clinical practice.
OncoLink

References


Bultz, B.D. & Johansen, C. (2011). Screening for Distress, the 6th vital sign: where are we, and where are we going? Psycho-Oncology, 20(6), 569-571.


