

Distress: Assessing the effects of coping with cancer

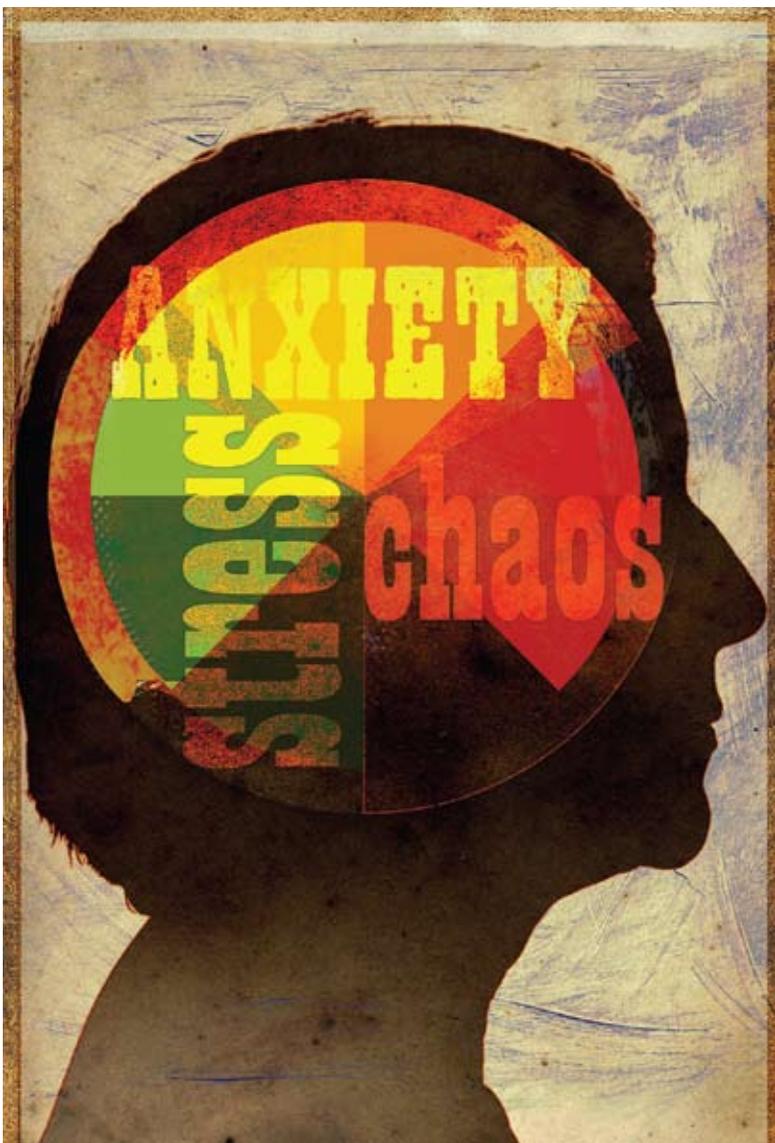
A cancer diagnosis and its treatment can cause high levels of distress. Nurses should assess patients frequently and know how to intervene promptly.

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Cancer has been known for many years as a stressful diagnosis that can challenge successful treatment of the disease. Screening for distress suggests that 40% to 50% of adults with cancer treated in the outpatient setting experience significantly high levels of distress that interferes with their decision-making skills and adherence to treatment protocols and schedules.¹⁻⁴

A panel group was established to investigate the issues surrounding the distress incurred with a diagnosis of cancer and its treatment, and in 1999, the National Comprehensive Cancer Network (NCCN) developed clinical guidelines for distress management in the cancer patient.⁵ These guidelines are reviewed and updated annually, with recommendations for implementation in a variety of settings. Although widely recognized as a standard from which to benchmark quality measures, the NCCN guidelines remain just that—guidelines. Despite being an important indicator on how a patient may respond during treatment, a standard implementation mechanism for utilizing the guidelines in most oncology practices has not been established. The NCCN guidelines encompass the stages of disease, patient care settings, and institutional services and policies.⁶ The guidelines' major recommendations can be described as follows.

Patients should be monitored for distress. The level and nature of a patient's distress should be identified and treated promptly. Recognition and documentation processes for distress should



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be a part of patient care at all stages of the disease in all clinical settings.

Distress screening should be performed at the initial visit and at appropriate intervals during treatment. In addition, screening should be performed when clinically indicated, especially when disease status has changed.

Distress assessment and management should follow established clinical practice guidelines. The NCCN recommends that institutions develop interdisciplinary committees to implement the standards of care outlined by its guidelines.

Oncology care providers need knowledge and skills in assessing and managing patient distress. Education and training programs should be developed to ensure clinicians can acquire these skills.

Institutions should have licensed mental health care professionals and certified chaplains readily available. Reimbursement for mental health care should be included in medical care contracts with third party payers.

Patients and their families should be informed that distress management is an integral part of total cancer care. Treatment teams should be concerned with assessing patients' distress levels.

Assessment of the psychosocial domain should be included in clinical health outcomes measurements. Continuous quality improvement projects should include distress management programs/services provided by the institution.

MEASURING DISTRESS

Nurses are in a unique position to make a difference in screening for and management of the distress that patients often experience but may not report. More patients are seen by nurses at each visit than by physicians, especially those patients undergoing frequent chemotherapy or daily radiation treatments; therefore, nurses are at the forefront for asking the patient pertinent questions regarding symptoms of distress (ie, sleep disturbances, eating disorders, fatigue, feelings of hopelessness or anxiety) he or she may be experiencing. Patients can rate their distress with a distress thermometer, which is a simple tool that works similar to self-rating pain on a scale of 1 to 10. A more formal and involved questionnaire can be used to follow up this initial assessment if specific areas of distress need to be identified.^{7,8}

Screening for distress should begin at the point of first contact with the patient, usually at diagnosis. A distress thermometer allows nurses to very quickly identify issues in most patients; however, a quick assessment does have its drawbacks. A distress thermometer can only indicate that distress levels are elevated as perceived by the patient using the tool; it cannot clearly identify the issues causing the patient distress. In some cases, family members are also asked to

rate the patient's distress level. A comparison of the family member's report and the patient's self-report may provide a more accurate assessment of the level of distress the patient is experiencing.

POST PRIMARY CANCER CARE

Follow-up can be achieved in many ways after an elevated distress rating is identified. Most patients are referred back to their physicians, and the nurse notifies the patient's doctor of possible issues to follow up. In addition, a referral to a social worker, support group, or mental health professional may be given depending on which support services are available

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within the practice or service setting. The National Cancer Institute (NCI) recommends including social work, mental health professionals (psychology and psychiatry as needed), palliative care, and pastoral care in follow-up care after primary oncology care.⁹

Standardized follow-up assessment at subsequent visits should also be part of the nurses' responsibilities. Using the same tool for reassessment allows patient responses to be standardized, and interventional evaluations and continuous quality improvements are easier to correlate. Standard points along the continuum of care routinely considered ideal for reassessment are when treatment modalities change (surgery, radiation, and chemotherapy), at posttreatment and remission, at recurrence and palliative care, and survivorship.⁹ Whether patient reassessment involves one nurse or a series of nurses can be an issue, especially when the patient moves from one practice setting to another. But if the oncology team agrees that this assessment is needed, the information should be shared from setting to setting, thus standardizing care and (hopefully) maximizing treatment outcomes as well as patient and family satisfaction.

CONCLUSION

Implementation of distress measurement practices in cancer care's time has come. Instituting this practice in all care settings—private practice, as well as in-patient and out-patient units—will not be easy to accomplish. However, by agreeing to complete assessments along the continuum of care, utilize a standardized tool to measure distress, and

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have the required support services for managing identified distress and stressors, oncology care providers will better serve their patients. Nurses who know how to use the distress measurement tool can be the mechanism that integrates this practice into standard care. ■

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