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Commentary

# The NCCN Guideline for Distress Management: A Case for Making Distress the Sixth Vital Sign

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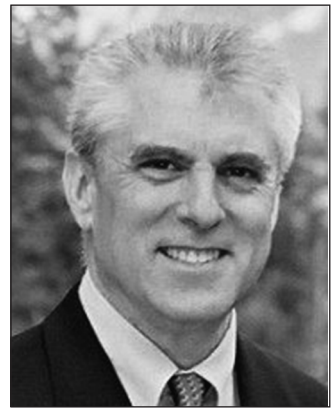

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Psychosocial care of patients has traditionally been seen as separate from routine medical care and has been criticized as being "soft" and lacking evidence. This traditional perspective continues in many settings, despite the fact that patients and families, when asked, state that emotional care is highly valued. The question of how to integrate psychosocial care into routine cancer care has also been an issue, partly because of the stigma associated with cancer.

In 1997, the National Comprehensive Cancer Network (NCCN) established a multidisciplinary panel to examine this problem.[1] Because patient and physician attitudes toward pain can pose similar barriers to care as can distress, the panel used as a model the rating system for assessing pain that resulted in successful improvement of pain management in the United States. The rating system's success seemed partly based on routinely using a single question to assess a patient's pain: "How is your pain on a scale of 0 to 10?" The system uses a score of 5 or higher as the indication to reassess pain medications or refer the patient for more expert management. This system is widely used, and patient self-report of subjective symptoms is now accepted as appropriate and reliable. Pain has become the fifth vital sign, after pulse, respiration, blood pressure, and temperature, ensuring that it is evaluated as part of routine care.

Drawing on this experience, the NCCN panel recommended a simple question to ask patients about psychosocial concerns. They found that *distress* was the best umbrella word to represent the range of emotional concerns patients with cancer experience and that it did not carry the stigma of other words sometimes used for emotional symptoms. Several studies have now validated the approach of asking, "How is your distress on a scale of 0 to 10?" and using a score of 4 or above as the trigger for further questions and possible referral to a psychosocial service.[2,3]

In 2004, the Canadian Federal Government's public health agency, Health Canada–Canadian Strategy for Cancer Control, approved "Emotional Distress as the 6th Vital Sign."[4] We propose that this practice should also be considered in the United States to ensure that psychosocial distress is routinely assessed as part of cancer care and managed according to the NCCN distress management guideline. This commentary outlines the potential benefits that can accrue for patients, families, and the health care system.

Over 2 years beginning in 1997, the NCCN's multidisciplinary panel developed the first set of standards and clinical practice guidelines for psychosocial care in cancer.[1] Because the panel included representatives from all major disciplines involved in clinical care (oncology, nursing, psychiatry, psychology, chaplaincy, social work, and patient advocacy), it was both highly effective and practical in its approach. The panel focused on the ambulatory setting, where most cancer care is given today. Based on these NCCN guidelines, a brief handbook was published in 2006 to guide oncology clinicians in managing psychiatric and psychosocial symptoms.[5]

## The NCCN Approach

The NCCN panel chose the word *distress* to describe the psychological, social, and spiritual (nonphysical) aspects of care because it does not carry stigmatizing connotations and because patients are comfortable with its use. Although people with cancer normally experience some level of distress, it can reach intolerable levels. Thus, *distress* can be considered to range from normal fears, worry, and sadness to disabling problems such as clinical depression, generalized anxiety, panic, isolation, or a spiritual or existential crisis.

The NCCN panel recognized that emotional distress should be part of routine care. The guideline provides an algorithm (see "Screening Tools for Measuring Distress" on page 72) to quickly identify patients with significant distress. Similar to the 0 to 10 scale for assessing pain, a visual analogue screening approach can be used to help patients rate their distress, becoming the sixth vital sign.[6–8] The 0 to 10 scale can be visually displayed as the Distress Thermometer (see page 72), and patients can rate their distress in the waiting room. The patients can also be asked, "How is your distress on a scale of 0 to 10?" A score of 4 or higher (a first-level inquiry) is a trigger for the oncologist or nurses to ask additional questions (a second-level inquiry) to determine the cause of distress and refer the patient to the proper psychosocial or supportive care service. Physicians and nurses can learn to use this rapid screening method routinely, ensuring that patients are asked about distress at each visit. The American Psychosocial Oncology Society, which endorses these guidelines, offers 4 free online lectures for nurses on using the distress thermometer (www.apos-society.org). The Distress Thermometer is accompanied by a Problem List (see page 72), in which patients are asked to note the nature and source of their distress (physical, social, psychological, or spiritual). In this way, the appropriate referral discipline (e.g., mental health, social work, pastoral counseling) can be identified easily.

Several studies were done to establish the reliability and validity of the Distress Thermometer as a screening instrument for distress (Table 1).[2,3,9–12] It is most often validated against the Hospital Anxiety and Depression Scale. The specificity and sensitivity found in the largest multicenter validation study suggest that a score of 4 or higher indicates the need for further evaluation,[2] although early data suggested a cut-off score of 5 or higher. Patients are comfortable using the Distress Thermometer and Problem List, and physicians see them as useful checklists to prompt and guide questions about physical and psychological symptoms.[11]

**Table 1 Distress Thermometer Validation Studies**

| Author | No. of Patients | Comparison Measure | Cut-off Score |
|---|---|---|---|
| Roth et al.[9] (1998) | N = 121 prostate carcinoma with advanced disease | HADS | ≥5 |
| Jacobsen et al.[2] multicenter (2005) | N = 380 outpatient | HADS, BSI-18 | ≥4 |
| Hoffman et al.[12] (2004) | N = 68 outpatient | BSI & BSI-18 | ≥4–6 |
| Ransom et al.[3] (2006) | N = 491 pretransplant | CES-D, STAI-S | ≥4 |

In 2003, the NCCN Distress Management Panel published more fully developed standards for psychosocial care and distress management, which established for the first time a minimal set of quality measures for managing distress:[13]

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease.
- All patients should be screened for distress during the initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status such as remission, recurrence, disease progression.
- Screening should identify the level and nature of the distress.
- Distress should be assessed and managed according to clinical practice guidelines.

## How Common is Distress in Patients with Cancer?

Distress clearly occurs at a significant level in at least one third of cancer patients,[14–16] with frequency and severity increasing with advanced stages of illness.[17,18] A large study using the Brief Symptom Inventory to screen for distress in almost 5000 cancer patients at Johns Hopkins found that 35% had significant levels of distress.[15] The rate for patients with lung cancer was greater, at 45%. Similarly, in almost 3000 patients at the Tom Baker Cancer Centre in Alberta, Canada, high levels

Commentary

of fatigue were found in 49% of all patients, pain in 26%, anxiety in 24%, and depression in 24%, along with significant financial hardship.[16] In a Jordanian sample of hospitalized cancer patients, the prevalence of distress was 70%.[17] Similar overall rates are reported in other parts of the Middle East,[20–22] several European countries,[11, 23, 24] South America,[25] and Asia.[26–29]

## Funding for Psychosocial Services

Funding for psychosocial services remains limited. Budget cuts in the United States usually involve social work and mental health first, because these are viewed as the most expendable. In Canada, where health care is publicly funded and delivered, a 1999 survey of provincial cancer agencies found that less than 3% of the operating dollars of cancer centers were appropriated for psychosocial care, compared with 5% for cleaning services.[30]

In the United States, most cancer care has moved from the hospital to outpatient offices and clinics, but hospital psychosocial services did not move. Furthermore, new psychosocial counseling positions have not been added to meet the high volume of patients treated in the outpatient setting. This situation is largely related to poor reimbursement from government and private insurers for outpatient mental health and social services. Office practices often cannot generate the funds to support psychosocial care without grants or philanthropy. In a resource-rich country like the United States, this is an unacceptable policy. Reimbursing 80% of a patient's medical visit by Medicare and only 50% for a psychiatric or mental health visit is a major discrepancy that must be addressed.

Two events suggest progress. In June 2004, the U.S. President's Cancer Panel said "The Federal government should implement comprehensive health care reform, whose provisions should include coverage for psychosocial services, both during and after treatment, and reimbursement for a range of follow-up care, including that provided by nonphysicians."[31] Furthermore, in the 2005 Appropriations Bill, $1 million was allocated to undertake a major study by the Institute of Medicine (IOM), National Academy of Sciences, to examine the barriers to psychosocial services of patients with cancer and chronic illnesses.[32] The IOM committee began deliberating in July 2006 and should have forceful recommendations for policy changes by 2007, which should include a study of reimbursement issues.

Many insurance companies in the United States and health care administrators in Canada say the system cannot afford to pay for this "soft side" of cancer care. We suggest that this is not the case. The United States cannot afford to ignore the problem because the financial and human burdens become greater when these aspects of care are neglected. Patients who are significantly distressed require more time, contact, and emergency attention, and are often the most frustrating to the oncology team. Early diagnosis and treatment of emotional distress can reduce both patient symptoms and the strain on the oncology team.

## Economics of Psychosocial Care

Although clinical studies have shown that patients benefit from psychosocial care, fewer than 5% of distressed patients in busy clinics are diagnosed with this condition and receive any psychosocial treatment.[33,34] Studies have also shown that timely psychosocial care can be delivered without increasing overall cost.[35,36] A randomized trial in Canada[37] showed a 22% decrease in billings to the medical system as a result of psychosocial intervention in women with breast cancer, and a meta-analysis of 90 studies[38] showed that medical costs were offset when psychosocial care in medically ill patients improved. Because the World Health Organization estimates that the incidence of cancer in developed countries will double in the next 15 years and as the focus on chronic diseases, particularly cancer, increases and care becomes more patient-centered, the economics become more critical[39] and including distress management in routine care will become even more important.

Dr. David Beatty, Executive Director of the National Cancer Institute of Canada in 1993, stated that the most significant advance in cancer treatment in the past decade has occurred in psychosocial care.[40] However, emotional care of the cancer patient still has received only minor recognition within the formal cancer care system. Clearly, this policy must change.

## Summary

Recognizing that the "people part" of cancer care is a vital component of a compassionate high-quality cancer system makes ethical, emotional, and economic sense. A simple way to screen for distress is to use the

single-item question recommended by the NCCN; experience with pain management proves that this is a major step in the right direction. We propose that emotional distress should be declared the sixth vital sign in the United States, as in Canada, to ensure that distress management, like pain management, becomes a routine part of cancer care.

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