

Implementation of NCCN Distress Management Guidelines by Member Institutions

Paul B. Jacobsen, PhD,^a and Sean Ransom, PhD,^b *Tampa, Florida, and Laie, Hawaii*

Key Words

Psychological distress, clinical practice guidelines, screening

Abstract

Up to half of all adults with cancer experience clinically significant psychological distress and much of this distress goes unrecognized and untreated. As part of an effort to improve the care of cancer patients, the National Comprehensive Cancer Network (NCCN) has developed clinical practice guidelines for distress management that include recommendations about the evaluation and treatment of distress. These authors conducted a study to evaluate the implementation of these distress management guidelines by NCCN member institutions. The NCCN member institutions that treat adults were asked in April and May 2005 to describe their distress management practices, and 15 (83%) provided responses. Of these, 8 (53%) conduct routine distress screening for at least some patient groups, with 4 additional institutions (27%) pilot-testing screening strategies. However, only 20% of surveyed member institutions screened all patients as the guidelines recommend. In addition, whether institutions that conduct routine distress screening do so through standardized assessment methods is unclear, because 37.5% of institutions that conduct screening rely only on interviews to identify distressed patients. Findings suggest that most institutions consider screening patients' mental health concerns important and worthwhile, but that greater implementation of guideline recommendations is needed. (*JNCCN* 2007;5:99–103)

P psychological distress is common among cancer patients. Recent surveys suggest that 40% to 50% of adults with cancer seen on an outpatient basis experience clinically significant levels of distress.^{1–3} In addition to the suffering

it causes, heightened distress has been shown to be associated with poorer adherence to treatment recommendations,⁴ poorer satisfaction with care,⁵ and poorer quality of life across multiple domains.⁶ The importance of recognizing distress is underscored by the fact that several pharmacologic and nonpharmacologic interventions have been shown to be effective in preventing or relieving distress in cancer patients.⁷ Unfortunately, evidence indicates that clinically significant distress often goes unrecognized and untreated by oncology professionals.^{8–10}

As part of an effort to improve the recognition and treatment of distress in cancer patients, the National Comprehensive Cancer Network (NCCN) convened a panel in the late 1990s to formulate clinical practice guidelines for distress management. Representatives from each of the 19 member institutions met and developed consensus-based guidelines that were first published in 1999¹¹ and are updated annually. The guidelines include standards of care for distress management and specify clinical pathways that provide detailed recommendations about the evaluation and treatment of distress.

The primary goal of the current study was to evaluate progress in implementing these distress management guidelines by NCCN member institutions. The authors are unaware of any previous research that has directly addressed this issue. Certain aspects of the guidelines can be viewed as key indicators of progress in implementing the guidelines.

Two points relate to the standards of care. First, the standards stipulate that mental health professionals experienced in psychosocial aspects of cancer should be readily available to help patients.¹² Accordingly, each member institution should have mental health services available for patients. Second, the standards also stipulate that all patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated.¹² To be consistent with this standard, each member

From the ^aH. Lee Moffitt Cancer Center & Research Institute at the University of South Florida, Tampa, Florida; and Brigham Young University-Hawaii, Laie, Hawaii.

Submitted July 26, 2006; approved for publication August 18, 2006.

The authors have no financial interest, arrangement, or affiliation with the manufacturers of any products discussed in the article or their competitors.

Correspondence: Paul B. Jacobsen, PhD, H. Lee Moffitt Cancer Center & Research Institute, MRC-PSY, 12902 Magnolia Drive, Tampa, FL 33612. E-mail: jacobsen@moffitt.usf.edu

institution should routinely screen all patients for distress.

Two additional points relate to the process of screening for and evaluating distress in cancer patients described in the clinical pathways. First, the pathways indicate that the initial step in managing distress is administering a brief, self-reported measure to identify the severity and potential sources of distress.¹² Measures recommended to screen for distress include the single-item Distress Thermometer¹³ that asks respondents to rate their current level of distress on a scale ranging from 0 (“no distress”) to 10 (“extreme distress”). Adherence to this pathway would be evidenced by the use of a brief screening tool, such as the Distress Thermometer, to routinely screen for distress. Second, the pathways identify a clinical decision that should be made based on the initial evaluation of distress severity.¹² Patients experiencing moderate to severe distress should be referred for mental health, social work, or pastoral services as appropriate. For patients experiencing mild distress, continued management by the primary oncology team is considered appropriate. Therefore, each institution should have procedures that refer patients who are identified as distressed through routine screening to professionals with clinical expertise in psychosocial oncology.

To assess implementation of these aspects of the distress management guidelines, key informants at each NCCN member institution were asked to respond to a brief survey.

Methods

A survey developed by the authors was sent by way of electronic mail in April and May 2005 to institutional representatives appointed to the NCCN Distress Management Guidelines Panel. A decision was made not to obtain survey results from the one member institution serving only pediatric cancer patients (St. Jude Children’s Research Hospital), because instructions for completing the survey referred specifically to implementation of the guidelines in regards to adult cancer patients seen on an outpatient basis. (Sitman Cancer Center was not a member institution at that time and was therefore also not included.) In instances where an institution had more than one representative on the panel, a single representative was selected initially to complete the survey. If a response from the first institutional representative was not received

within 2 weeks after a reminder, another institutional representative (if applicable) was asked to complete the survey. In instances in which an institutional representative did not reply, attempts were made to identify and contact an individual at the institution involved in the delivery of psychosocial services who could complete the survey. Survey items focused on the availability of mental health services, the use of screening methods to identify distressed patients, and the providers of services if a distressed patient was identified.

Results

Responses were received from 15 of the 18 NCCN member institutions eligible for participation in the survey (83% response rate). The initial set of survey items focused on the availability and funding of mental health services at member institutions. All 15 institutions responding (100%) indicated that mental health services are available in their setting. A follow-up item sought information about the charge system used when mental health services are provided. The response options provided were: 1) no patients are charged for mental health services (either insurance or self-pay); 2) all patients are charged for mental health services (either insurance or self-pay); or 3) patients are charged depending on the mental health services they receive. Among the results, 3 institutions (20%) indicated that no patients are charged, 3 institutions (20%) indicated that all patients are charged, and 9 institutions (60%) indicated that patients were charged depending on the type of services they received. Qualitative information obtained from some member institutions indicated that the last category often reflected provision of services by clinical social workers at no charge to patients, but charges for services provided by other mental health professionals (e.g., psychiatrists and clinical psychologists).

The next set of survey items focused on determining implementation of recommendations that patients be screened routinely for distress. The initial item (“yes/no”) asked whether any patients at the institution were screened routinely for distress. Responses indicated that 8 institutions (53%) conducted routine screening for distress.

A follow-up question, directed to institutions that did not screen any patients for distress, sought information about why patients were not being

Implementation of NCCN Distress Management Guidelines

screened. Response options provided for this item were: 1) screening is not considered necessary or worthwhile; 2) would like to but do not have the resources to screen; 3) would like to but do not have the resources to see the patients who might be identified as distressed; or 4) other reason. Of the 7 institutions that did not conduct screening, the reasons identified were: 1) screening not considered necessary or worthwhile ($n = 1$; 14%); 2) not enough resources to see distressed patients who might be identified ($n = 1$; 14%); 3) neither enough resources to screen nor enough resources to see distressed patients who might be identified ($n = 1$; 14%). The 4 remaining institutions (58%) indicated that they were currently in the process of pilot-testing procedures for routine distress screening.

Two follow-up questions were directed to institutions currently screening patients routinely for distress. The first asked if patients were screened through interview or a self-reported measure. Of the 8 institutions conducting any routine screening, 3 (37.5%) used only an interview, 2 (25%) used only a self-report measure, and 3 (37.5%) used both an interview and a self-report measure. Of the 5 institutions using self-report measures to screen for distress, 3 (60%) used the Distress Thermometer, 1 (20%) used a battery of measures, and 1 (20%) did not provide additional information. The second question asked which patients were being screened: all patients (universal screening) or just patients with certain types of cancer or undergoing certain types of treatments. Of the 8 institutions conducting any routine screening, 3 (37.5%) screened all patients routinely and 5 (62.5%) screened just certain patients routinely. At the 5 institutions where just certain patients were being screened, the subgroups identified as being screened routinely varied considerably. Of these, 4 institutions (80%) indicated that routine screening included patients undergoing bone marrow transplantation, and 2 institutions (40%) indicated that routine screening included breast cancer patients. Other subgroups identified only by a single institution included patients with sarcomas, gynecologic cancers, hematologic malignancies, and melanoma.

The final survey question sought information about the disposition of patients identified as distressed through routine screening. The response options provided were: 1) nothing (the information collected is not used for clinical purposes); 2) patients seen only

by the oncologist or oncology nurse providing their cancer treatment; 3) patients seen by a mental health professional; or 4) other disposition. Of the 8 institutions conducting any routine screening, 0 (0%) indicated that nothing was done with the screening information, 0 (0%) indicated that the patient was seen only by an oncologist or oncology nurse, 1 (12.5%) indicated "other," and 7 (87.5%) indicated that the patient was seen by a mental health professional. In the 1 setting reporting "other," disposition depended on referrals being made by the oncologist or oncology nurse. In the 7 settings where patients were seen by a mental health professional, the professional disciplines involved in the care of patients identified as distressed via routine screening were: social work only ($n = 1$; 14%); social work and psychology ($n = 1$; 14%); social work and psychiatry ($n = 3$; 44%); social work, psychology, and psychiatry ($n = 1$; 14%); and social work, psychology, psychiatry, and pastoral care ($n = 1$; 14%).

Discussion

The results of this survey indicate considerable progress in implementing some aspects of the distress management guidelines, but more limited progress in implementing others.

On the positive side, all institutions surveyed indicated that mental health services were available in their setting. Moreover, most institutions had a system that did not charge fees for at least some types of mental health services. This feature suggests the relative absence of economic barriers to accessing a mental health professional at member institutions. Another positive finding was that 53% of member institutions were conducting at least some routine screening for distress, and an additional 27% were piloting procedures for routine screening. These rates, coupled with the finding that screening was considered unnecessary or not worthwhile at only one institution, suggests a general acceptance of routine screening for distress as part of clinical care.

A third positive finding involved the disposition of patients identified as distressed through routine screening. At all but one institution conducting screening, patients identified as distressed were referred routinely to a mental health professional. However, findings indicated considerable variability across institutions in the disciplines involved in

providing psychosocial services to distressed patients. Although social workers were said to be involved in delivery of psychosocial care at all of these institutions, 72% also reported the involvement of a psychiatrist, 42% the involvement of a psychologist, and 16% the involvement of a pastoral counselor.

Despite these achievements, several areas can be identified where progress in implementing the distress management guidelines has been limited. First and foremost is the finding that only 20% of the member institutions surveyed were currently screening all patients for distress as recommended by the guidelines. A second area of concern relates to the methods used to identify distressed patients. Among institutions conducting any routine screening, 37.5% relied only on interviews for identifying distressed patients. To the extent that these interviews are not standardized and have not been systematically evaluated, their sensitivity and specificity in identifying distressed patients are unknown. In contrast, several studies have evaluated brief screening measures such as the Distress Thermometer for their usefulness in identifying clinically significant distress,^{1,2,14,15} and objective procedures have been established to classify patients as distressed based on their self-reports.

The results of the current survey suggest several future directions for examining implementation of NCCN distress management guidelines. One important direction would be to examine the extent to which the guidelines have been implemented outside the NCCN. It would be interesting to examine guideline implementation at National Cancer Institute (NCI)-designated cancer centers because they represent most of the leading cancer treatment facilities in the United States. It would also be interesting to examine implementation among a sample of community-based cancer centers where resources for provision of psychosocial care may be more limited than at NCCN member institutions and NCI-designated cancer centers. Another direction would be to examine implementation of the guidelines with greater precision than the current survey. For example, collecting quantitative data from each institution, rather than relying on key informants' survey responses, would allow calculation of the actual percentage of patients screened for distress at each institution and, of those identified as distressed, who received referral to a mental health professional. Yet another future direction would be to resurvey the same 15 NCCN member

institutions that completed the current survey to determine if changes have occurred in implementing the distress management guidelines.

The results of the current survey also identify the need to explore ways to promote greater implementation of the guideline recommendation to screen all patients for distress. Responses from several institutions indicating that insufficient resources are available to screen patients suggest that ways to reduce the personnel and effort required to conduct screening must be explored. Use of automated methods, such as computer kiosks positioned in waiting areas, may be one way to obtain information about distress with minimal professional involvement. Studies have shown that the use of computers to collect self-reported data on quality of life is acceptable to patients and yields comparable information to that collected using paper and pencil methods.^{16,17} Greater implementation may also be facilitated by stronger evidence that better outcomes result from using the guidelines. Currently, much evidence supporting the guidelines is based on clinical experience. Studies are needed to test the hypothesis that care delivered in a manner consistent with the NCCN distress management guidelines (e.g., routine screening followed by referral of distressed patients to mental health professionals) results in better control of distress than care delivered inconsistently with the guidelines. Evidence to support this hypothesis could encourage institutions that have lagged in implementing the guidelines to reorganize their patterns of care to be consistent with an approach that yields better outcomes.

References

1. Hoffman BM, Zevon MA, D'Arrigo MC, et al. Screening for distress in cancer patients: the NCCN rapid-screening measure. *Psychooncology* 2004;13:792–799.
2. Jacobsen PB, Donovan KA, Trask PC, et al. Screening for psychological distress in ambulatory cancer patients. *Cancer* 2005;103:1494–1502.
3. Trask PC, Paterson A, Riba M, et al. Assessment of psychological distress in prospective bone marrow transplant patients. *Bone Marrow Transplant* 2002;29:917–925.
4. Kennard BD, Smith SM, Olvera R, et al. Nonadherence in adolescent oncology patients: preliminary data on psychological risk factors and relationships to outcome. *J Clin Psychol Med Settings* 2004;11:30–39.
5. Von Essen L, Larsson G, Oberg K, et al. 'Satisfaction with care': associations with health-related quality of life and psychosocial function among Swedish patients with endocrine gastrointestinal tumours. *Eur J Cancer Care (Engl)* 2002;11:91–99.

Implementation of NCCN Distress Management Guidelines

6. Skarstein J, Aass N, Fossa SD, et al. Anxiety and depression in cancer patients: relation between the Hospital Anxiety and Depression Scale and the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire. *J Psychosom Res* 2000;49:27–34.
7. Jacobsen PB, Donovan KA, Swaine ZN, et al. Management of anxiety and depression in cancer patients: toward an evidence-based approach. In: Chang AE, Ganz PA, Hayes DF, et al., eds. *Oncology: An Evidence-Based Approach*. New York: Springer, 2006:1552–1579.
8. McDonald MV, Passik SD, Dugan W, et al. Nurses' recognition of depression in their patients with cancer. *Oncol Nurs Forum* 1999; 26:593–599.
9. Passik SD, Dugan W, McDonald MV, et al. Oncologists' recognition of depression in their patients with cancer. *J Clin Oncol* 1998; 16:1594–1600.
10. Sollner W, DeVries A, Steixner E, et al. How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counseling? *Br J Cancer* 2001;84:179–185.
11. National Comprehensive Cancer Network. NCCN practice guidelines for the management of psychosocial distress. *Oncology (Williston Park)* 1999;13:113–147.
12. Holland JC, Andersen B, Breitbart WS, et al. The NCCN Distress Management Guidelines, version 1, 2007. Available at: www.nccn.org/professionals/physician_gls/PDF/distress.pdf. Accessed September 21, 2006.
13. Roth AJ, Kornblith AB, Batel-Copel L, et al. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;82:1904–1908.
14. Akizuki N, Akechi T, Nakanishi T, et al. Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. *Cancer* 2003;97:2605–2613.
15. Ransom S, Jacobsen PB, Booth-Jones M. Validation of the Distress Thermometer with bone marrow transplant patients. *Psychooncology* 2006;15:604–612.
16. Gil KM, Frasure HE, Hopkins MP, et al. Effect of method of administration on longitudinal assessment of quality of life in gynecologic cancer: an exploratory study. *Health Qual Life Outcomes* 2005;3:6.
17. Mullen KH, Berry DL, Zierler BK. Computerized symptom and quality of life assessment for patients with cancer. Part II: acceptability and usability. *Oncol Nurs Forum* 2004;31:E84–E89.