

Progress in the Implementation of NCCN Guidelines for Distress Management by Member Institutions

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Abstract

A 2005 survey of NCCN Member Institutions was among the first studies to evaluate the extent to which key elements of the NCCN Clinical Practice Guidelines in Oncology for Distress Management were being implemented as part of routine clinical practice. This study seeks to characterize current implementation of the guidelines by NCCN Member Institutions 7 years after the original study. Institutional representatives appointed to the NCCN Distress Management Panel were asked to complete an online survey in June 2012. The survey was similar to the 2005 survey, except that it solicited additional details about screening procedures. The survey was completed by representatives from 20 of 22 NCCN Member Institutions (91%). (Note: In this calculation, 1 consortium cancer center was counted as 2 NCCN Member Institutions.) Responses indicate that routine screening for distress is being conducted at 70% of institutions, with 25% screening inpatients and 60% screening outpatients. Among institutions screening outpatients, 50% screen all outpatients and 50% screen only certain subgroups of outpatients. In terms of method, 85% of institutions conducting screening use a patient self-report measure either alone or in combination with an interview; the Distress Thermometer is used at 59% of institutions that use a self-report measure. Findings show modest progress since 2005 in implementing guideline recommendations regarding distress screening, with a 7% increase in institutions conducting any routine screening and a 10% increase in institutions screening all outpatients routinely. Greater progress is evident in the use of self-report measures as part of screening, with a 23% increase in their use alone or in combination with an interview. (*JNCCN* 2013;11:223–226)

Editor’s Note: NCCN comprises 21 NCCN Member Institutions. For this survey, the authors counted 1 consortium cancer center as 2 institutions, resulting in 22 institutions.

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Submitted August 15, 2012; accepted for publication December 6, 2012.

The authors have disclosed that they no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors.

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There has been growing recognition in recent years that psychosocial care is an important component of the comprehensive care of people diagnosed with cancer. A notable example is the 2008 publication of an Institute of Medicine report titled, “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.”¹ Among the report’s main conclusions was that, despite evidence of the effectiveness of psychosocial services, many patients do not receive help for problems that would benefit from this type of care (eg, emotional and practical problems). To address this issue, the report recommended that standards for the quality of cancer care include the provision of appropriate psychosocial health services. Toward this end, the report outlined a model for the delivery of care in which processes are in place to identify patients’ psychosocial health needs and link them with needed services.

These recommendations are predated in many ways by the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Distress Management first issued in 1999² and updated annually (available in this issue; to view the most recent version, visit NCCN.org).³ These guidelines were developed based on the recognized need for better management of distress and with the intent of promoting best practices for the psychosocial care of patients with cancer. The guidelines include standards of care for distress management and provide detailed recommendations in the form of clinical pathways about the evaluation and treatment of distress.

To evaluate the extent to which NCCN Member Institutions had implemented key aspects of these guidelines, the authors created and distributed a survey in 2005 to institutional representatives on the NCCN Distress Management Panel;⁴ results from that survey are summarized later in this report. With the growing recognition of the importance of psychosocial care, the authors were interested in learning whether member

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institutions had made progress in implementing the guidelines. Accordingly, they conducted a similar survey in 2012. The results of the new survey and comparisons with results of the 2005 survey are discussed.

Methods

The authors developed a survey similar in content to the one used in 2005⁴ but designed to solicit more details about screening procedures. Survey items focused on the availability of mental health services, screening methods used to identify distressed patients, and the providers of services if a distressed patient was identified. Additional information about item content is presented with the results and a copy of the survey is available upon request.

Once created, the survey was formatted for Web-based completion by the Moffitt Cancer Center Survey Methods Core. A letter containing a link to the Web-based survey was sent via electronic mail in June 2012 to each institutional representative appointed to the NCCN Distress Management Panel. For institutions that had more than 1 representative on the panel, a single representative was selected to complete the survey. Multiple reminders were sent via electronic mail in June and July 2012 to institutional representatives who did not complete the survey in response to the initial request.

Results

Responses were received from representatives at 20 of 22 NCCN Member Institutions, reflecting a 91% response rate. (Note: In this calculation, 1 consortium cancer center was counted as 2 NCCN Member Institutions.) The initial set of survey items focused on the availability and funding of mental health services. Responses indicated that mental health services are available at 19 of 20 (95%) institutions. With respect to the charge system used when mental health services are provided, responses indicated that 1 institution (5%) does not charge patients for mental health services, 4 institutions (21%) charge routinely for mental health services, and 14 institutions (74%) charge depending on the type of mental health service provided. Several representatives who indicated that charges are made depending on the type of service noted that patients are not charged for services provided by

social workers, but are charged for those provided by clinical psychologists and psychiatrists. The response from the representative of the sole institution where patients are not charged for mental health services indicated that this institution is in the process of transitioning to a system in which patients will be charged routinely for mental health services.

The next set of survey items focused on whether, consistent with the current guidelines, patients are screened routinely for distress. Responses indicated that 14 of 20 institutions (70%) conduct routine screening for distress. A follow-up survey item directed to institutions where routine screening is not conducted sought information as to why patients are not being screened. Among these 6 institutions, 1 representative indicated that the institution has neither the resources to conduct screenings nor the resources to see patients who might be identified as distressed, and 2 representatives indicated that their institutions are currently piloting routine distress screening. Among the 3 institutions that indicated “other” as the reason for why patients are not screened, 2 representatives noted the lack of institutional commitment to routine screening and 1 representative cited no personal knowledge of why patients are not screened.

Two follow-up survey items were directed to institutions that routinely screen patients for distress. Responses indicated that, among these 14 institutions, 5 (36%) are screening inpatients routinely and 12 (86%) are screening outpatients routinely. Among those institutions screening outpatients routinely, responses indicated that 6 institutions (50%) are screening all outpatients and 6 institutions (50%) are screening only certain subgroups of patients. The patient subgroups identified as being screened routinely on an outpatient basis varied considerably across institutions. Of the 6 institutions, 4 (67%) indicated that all patients with breast cancer are being screened routinely. Other subgroups identified by individual institutions include patients with gynecologic, head and neck, and lung cancers; blood and marrow transplant recipients; neuro-oncologic and urologic presurgery patients; and patients in clinics dedicated to psychiatric, supportive, palliative, and survivorship care.

The next set of survey items was also directed at institutions that screen patients routinely for distress and concerned the methods used to screen. Among these 14 institutions, 2 (14%) use an interview only,

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9 (64%) use a self-report measure only, and 3 (21%) used both an interview and a self-report measure. Of the 12 institutions using self-report measures, 5 (42%) use the Distress Thermometer only, 2 (17%) use the Distress Thermometer combined with other self-report measures, and 5 (42%) use other self-report measures. Among the same 12 institutions, 8 (75%) administer the self-report measure via paper and pencil, 6 (50%) administer it via a tablet, and 3 (25%) use the Internet. These figures sum to greater than 100% because some institutions use more than one method.

The next set of survey items sought information about the triaging and disposition of patients identified as distressed. Among the 14 institutions conducting routine screening, responses indicated that at 1 institution (7%) patients are triaged automatically based on computer-generated results, at 12 institutions (86%) personnel review the screening result and generate a referral, and at 1 institution (7%) both methods of triage are used. With respect to the disposition of patients identified via routine screening as distressed, at no institution is nothing done with the screening information, at 1 institution (7%) the patients are seen only by an oncologist or oncology nurse, and at 13 institutions (93%) the patients are seen by a mental health professional. In the 13 settings where distressed patients are seen by a mental health professional, the professional disciplines potentially involved are social work (n=11; 85%), psychology (n=10; 77%), psychiatry (n=9; 69%), and chaplaincy (n=2; 15%). In 13 of 14 institutions (93%) where patients are screened routinely, more than 1 of these disciplines may be involved in the care of distressed patients. The exception is 1 institution where social workers are the sole providers of mental health services.

The last 2 survey items inquired about whether patients are rescreened for distress and, if so, at what intervals and frequency. Among the 14 institutions that screen routinely, 11 (79%) rescreen patients for distress. Among these 11 institutions, the intervals and frequency varied considerably and included every 30 days or more, every 3 weeks, at each outpatient visit, annually, and at the next hospital admission.

Discussion

The overlap in content between the current survey and the one conducted in 2005 of NCCN Member Institutions⁴ permits direct comparison on several

items. Survey responses indicated that mental health services were currently available at all but 1 institution. This finding compares unfavorably with the 2012 survey, which showed that mental health services were available at every institution. With respect to the charge system used when mental health services are provided, fewer institutions now provide services free of charge (20% in 2005 vs. 5% in 2012), a similar percentage of institutions now charge all patients for services (20% in 2005 vs. 20% in 2012), and more institutions now charge patients depending on the services received (60% in 2005 vs. 74% in 2012).

Routine screening for distress as part of clinical care seems to have been more widely implemented over time. This change is evidenced by the increase from 53% in 2005 to 60% in 2012 in the percentage of institutions that conduct any routine outpatient screening. Most of this change reflects an increase in the percentage of institutions reporting that all outpatients are screened routinely (20% in 2005 vs. 30% in 2012). The percentage of institutions reporting that they only screen specific subgroups of outpatients has remained relatively constant (33% in 2005 vs. 30% in 2012). The current survey also found that 36% of institutions are screening some or all inpatients for distress. Comparable data on rates of inpatient screening are not available from the 2005 survey. The finding that 79% of institutions that screen for distress subsequently rescreen patients also indicates an increased awareness of the value of screening. The variety of intervals and frequencies reported indicates that no standardized approach yet exists for when and how often patients are rescreened.

Fewer institutions than previously reported (28% in 2005 vs. 17% in 2012) indicated that they lacked the resources to screen or provide services to distressed patients. Although responses indicated that no member institution considered screening unnecessary or not worthwhile, 33% of those not performing screening attributed it to a lack of institutional commitment.

Consistent with the growing evidence regarding the usefulness of brief screening measures in identifying clinically significant distress,⁵ the use of these measures seems to have gained greater acceptance over time. Among institutions conducting any routine screening, an increase was seen in the percentage that used a self-report measure (either alone or in combination with an interview) rather than an interview alone (63% in

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2005 vs. 86% in 2012). Most of this increase reflected the greater use of self-report measures alone (25% in 2005 vs. 64% in 2012) rather than the combined use of self-report and interview measures (38% in 2005 vs. 21% in 2012).

Similar to results of the earlier survey, the single-item Distress Thermometer⁶ was the most commonly used self-report measure among institutions performing any screening. Findings from the current survey also suggest the increased use of emerging technologies to facilitate screening and referral practices. Although most institutions using self-report measures administer them via paper and pencil, nearly as many institutions are using tablet or Web-based applications in place of or in addition to paper and pencil administration. Additionally, 14% of institutions are now triaging distressed patients using automated processes to generate a referral.

Similar to the previous survey results, all but 1 institution that routinely screens patients refer distressed patients to mental health services. Social workers continue to play a prominent role in the delivery of psychosocial care. However, results of the current study also indicate an increased role for psychologists as providers of services. In settings where patients are seen by a mental health professional, the percentage of institutions in which psychologists are involved in the care of patients increased from 43% in 2005 to 77% in 2012.

Although informative, the current survey and the comparisons with the previous survey have several limitations. First, some NCCN Member Institutions did not participate in one or both of the surveys. Although high rates of participation were achieved (83% in 2005 and 91% in 2012), findings should be considered representative only of the subset of institutions that provided responses. Second, because of changes in NCCN membership and variability in which institutions completed the 2005 and 2012 surveys, the comparisons reported do not reflect changes over time at the same set of institutions. Third, the limited number of NCCN Member Institutions precludes conducting meaningful statistical comparisons of changes over time. Fourth, the responses obtained correspond to the views of the institutional representative who completed the survey. Whether an on-site audit of screening practices at each institution would yield similar results remains unknown.

Conclusions

Findings from the current survey indicate that nearly all NCCN Member Institutions continue to follow the NCCN Guidelines for Distress Management regarding the triaging and disposition of distressed patients. Beyond this, modest progress has occurred since 2005 in implementing guideline recommendations regarding screening for distress, as shown by the 7% increase in institutions conducting any routine screening and the 10% increase in institutions screening all outpatients routinely. Greater progress can be seen in the use of self-report measures as part of screening, with a 23% increase since 2005 in the use of these measures alone or in combination with an interview. A major impetus for additional progress will be the standards for patient-centered care that were issued in 2011 by the American College of Surgeons Commission on Cancer,⁷ a body that accredits more than 1500 hospitals in the United States. Among the new standards is one specifying that local oversight committees develop and implement processes for psychosocial distress screening and referral for the provision of psychosocial care. Plans to monitor compliance with these standards as part of the accreditation process should provide strong motivation for NCCN Member Institutions and others to complete the implementation of elements of the NCCN Guidelines for Distress Management related to distress screening and care of distressed patients.

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