

Screening for Psychosocial Distress: A National Survey of Oncologists

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In 1999, the National Comprehensive Cancer Network (NCCN) first released consensus-based guidelines for managing psychosocial distress¹; this term was chosen by the NCCN as a nonstigmatizing umbrella term to include emotional, psychological, and social difficulties along with actual psychiatric disorders. Situated within the supportive care guidelines, recommendations for managing psychosocial distress were grouped with those for other such cancer-related symptoms as pain, nausea, and fatigue.

For the cancer patient, mental health issues range from depression triggered by diagnosis or prognosis, anxiety about treatment decisions, and family stress to worry about the financial or professional repercussions of cancer treatment on daily life. Oncologists are aware that successful coping involves various adaptive responses and mobilization of personal and community resources. The NCCN guidelines for distress¹ recognize the pivotal role of oncologists in identifying, evaluating, and treating the psychosocial needs of patients and in referring them to appropriate mental health professionals, as needed.

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Abstract Little is known about the dissemination and uptake of National Comprehensive Cancer Network (NCCN) guidelines for psychosocial distress in oncology practice. This study surveyed oncologists about their awareness of NCCN guidelines on psychosocial distress and their methods of screening patients for distress. In all, 1,000 oncologists practicing in the United States who were members of the American Society of Clinical Oncology were asked to complete an anonymous questionnaire. Predictors of routine screening for distress were identified using logistic regression. Overall, 46% (448/965) of the oncologists responded. Almost two thirds (63.4%) practiced in the community, 27.2% practiced in cancer centers, and 6.9% practiced in hospitals. Less than one-third (32.3%) reported being at least somewhat familiar with NCCN guidelines. Two-thirds (65.0%; 95% confidence interval, 60.6-69.4) reported screening patients for distress routinely, but only 14.3% used a screening instrument. Independent predictors for screening patients for distress included availability of mental health services, knowledge of NCCN guidelines, experience, lack of time, uncertainty about identifying distress, and female gender of the practitioner. NCCN guidelines for psychosocial distress do not appear to be widely disseminated. Whereas the majority of oncologists reported routinely screening patients for distress, only a small percentage followed the guidelines by using a screening instrument. Future efforts should focus on the dissemination and validation of the NCCN guidelines.

Routine screening for psychosocial distress is a key recommendation of the NCCN guidelines. Unfortunately, numerous studies have shown that distress may go undetected in oncology visits.²⁻⁵ Whereas research on the effects of screening for distress in primary care clinics has not shown consistent benefit, the impact of screening in oncology clinics may be very different. Patients treated in oncology clinics have a higher prevalence of distress; these individuals have more frequent and intense office visits, and their distress may be directly related to their medical treatment. In many cases, their care involves a multidisciplinary team.

Distress experienced by cancer patients is associated with decreased medical adherence, greater desire for death, increased morbidity, lengths of

Table 1
Characteristics of Respondents

CHARACTERISTIC	VALUE
Age, mean years (SD)	50.26 (9.62)
Oncology specialty, n (%)	
Medical	431/439 (98.2%)
Surgical	0
Radiation	5/439 (1.1%)
Medical/radiation	3/439 (0.7%)
Practice setting, n (%)	
Cancer center	122/448 (27.2%)
Hospital	31/448 (6.9%)
Community	284/448 (63.4%)
Other	5/448 (1.1%)
More than one site	4/448 (0.9%)
Gender, n (%)	
Male	334/441 (75.7%)
Female	107/441 (24.3%)
Race/ethnicity, n (%)	
White	364/440 (82.7%)
Black	6/440 (1.4%)
Asian	51/440 (11.6%)
Native Hawaiian/Pacific Islander	1/440 (0.2%)
Native American	0
Latino/Hispanic	11/423 (2.6%)
Years in practice, n (%)	
In training	6/448 (1.3%)
< 5 years	55/448 (12.3%)
5–9 years	60/448 (13.4%)
10–19 years	144/448 (32.1%)
≥ 20 years	183/448 (40.8%)
Hours per week of seeing patients, mean (SD)	41.35 (17.66)

hospital stays, and, possibly, mortality.^{6–9} Recent evidence suggested that models that include the systematic diagnosis and treatment of distress through collaborative management result in lower cancer mortality.¹⁰

Although the NCCN guidelines have been available for eight years, little is known about their impact on oncology practice. Research to date primarily worked toward validating the Distress Thermometer, a one-item tool that uses a 0–10 scale to screen for distress.¹¹ Otherwise, information on the dissemination of the guidelines and their acceptance by the practicing oncology community largely is unknown.

This study surveyed oncologists across the United States about both their awareness of the NCCN guidelines for distress and their methods of screening patients for psychosocial distress. Previous studies investigated how oncologists recognize patient distress; however, this study was the first to explore the steps oncologists take to detect distress. Unfortunately, distress may go unrecognized because of a variety of processes that range from use of inaccurate detection methods to avoidance of psychosocial issues. Identifying the contribution of each process is

Table 2
Reported Methods of Screening

SCREENING METHOD	ONCOLOGISTS, n (%)
Asking direct questions	271/447 (60.6%)
Observing patients' moods	255/447 (57.0%)
Through patients' histories	236/447 (52.8%)
Talking with family	198/447 (44.2%)
Using screening instrument	64/447 (14.3%)
Patients meet with mental health professional	29/447 (6.5%)

critical in developing targets for improved recognition of these issues and, subsequently, their care.

Methods

POPULATION

The majority of the American Society of Clinical Oncology's (ASCO's) 17,000 members from the United States are medical oncologists. We randomly selected 1,000 oncologists from the association's annual membership directory to receive our survey instrument; we excluded practitioners who primarily treated children. To increase regional representation of the sample, we first stratified the sample by state and then selected oncologists within each state. The same sampling fraction was used in each state stratum, so no states were overrepresented.

SURVEY INSTRUMENT DEVELOPMENT

During 2004–2005, the survey instrument was developed using two waves of pilot testing—one from within our institution ($n = 91$) and the other from a broader sample of Massachusetts oncologists ($n = 99$). Pilot tests were conducted online using Zoomerang (Zoomerang zPro, 2004; Market-Tools; San Francisco, Calif), a commercially available tool for online surveys. Feedback from respondents and preliminary data analysis were used to test content validity. The pilot data were not included in the final sample.

The final survey consisted of 21 questions about observed rates of distress, availability of mental health services, screening for distress, barriers to screening, management of the condition, and knowledge of NCCN guidelines. Most items asked multiple-choice questions or requested numerical estimates. Free-text responses were elicited for items on barriers to screening, helpful resources for screening, and questions used to identify distress.

MODE OF DATA COLLECTION

The final survey was conducted online from September 12, 2005, through November 15, 2005. In light of the response, two paper mailings also were sent to nonresponders from January 2006 to May 2006. The survey closed on July 15, 2006.

The online and mail surveys were identical. There were no differences in practice settings between online and mail respondents. A \$10 gift certificate to Amazon.com was offered

as an incentive to complete the online survey; the final mailing offered a \$20 gift certificate. This study was approved by our institutional review committee.

DATA ANALYSES

The rate of reported screening was determined by calculating 95% confidence intervals (CIs). Free-text responses for barriers to screening, about helpful resources for screening, and to questions used to identify distress were analyzed qualitatively for the emergence of common themes. Initial univariate analyses were conducted to test differences among groups using chi-square for categorical variables and *t*-tests and analysis of variance for continuous variables. Those variables associated with reported routine screening at the 0.05 significance level in the univariate analyses were entered into a logistic regression model to determine independent predictors of routine screening. Similar analyses were done to identify predictors of reported use of a screening instrument.

Results

RESPONSE RATE

Of 1,000 e-mail versions of the survey sent to potential respondents, 21 were returned because of invalid addresses; 20 potential respondents declined participation. Of mailed surveys, nine were returned because of invalid addresses, and two were returned after the study closed; four oncologists declined participation. Of the remaining sample ($n = 965$), 448 (46.4%) oncologists responded. There were 189 online responses and 259 mail responses.

RESPONDENTS

Demographics of respondents are summarized in Table 1. Gender and racial/ethnic demographics were fairly representative of the ASCO membership list.

KNOWLEDGE OF NCCN GUIDELINES

Less than 10% (7.4%, 33/445) of oncologists reported being “very familiar” with NCCN guidelines on distress, and 24.9% (111/445) reported being “somewhat familiar” with them. Almost one third (30.6%, 136/445) reported having “heard of the guidelines but not seen them,” and 37.1% (165/445) reported being “not at all familiar” with the NCCN guidelines. After Bonferroni correction for multiple comparisons, knowledge of NCCN guidelines was not associated with practice setting, years of experience, hours of patient care per week, or oncologists’ gender.

ROUTINE SCREENING FOR DISTRESS

Two-thirds (65.0%, 290/446; 95% CI, 60.6–69.4) of the respondents screened their patients for distress routinely. Screening methods are summarized in Table 2.

Asking direct questions was the most common method that oncologists used to detect distress in their patients; the five most frequent questions asked were “How are you coping?” (31%), questions about sleep (28%), “Are you depressed?”

Table 3

Barriers to Screening for Distress ($n = 448$)

BARRIER	PROPORTION OF ONCOLOGISTS, n (%)
Lack of time	341/448 (76.1%)
Limited referral resources	219/448 (48.9%)
Patients’ unwillingness to discuss distress	185/448 (41.3%)
Uncertainty about treatment options	103/448 (23.0%)
Uncertainty about identifying distress	102/448 (22.8%)
Uncomfortable discussing distress	23/448 (5.1%)
Psychosocial interventions not effective	8/448 (1.8%)
Other providers’ responsibility	6/448 (1.3%)

(22%), questions about appetite (15%), and “How do you feel?” (14%). A minority of those who screened used a screening instrument (22.1%, 64/290; 95% CI, 17.3–26.9), representing 14.3% (64/447; 95% CI, 11.0–17.6) of all respondents.

Reported routine screening for distress was associated with oncologists also reporting higher observed rates of distress ($P = 0.04$) and of distress warranting treatment ($P = 0.001$).

BARRIERS TO ROUTINE SCREENING FOR DISTRESS

Reported barriers to routine screening for distress are summarized in Table 3. Two-thirds of respondents reported that having psychosocial staff to accept referrals (66.5%, 298/448) and having a brief screening instrument (66.3%, 297/448) would be helpful in routine screening for distress. About half of the responding oncologists reported that having more staff to help with the screening (51.3%, 230/448) and more training to identify distress (42.9%, 192/448) would be helpful. Almost all respondents reported that they would at least consider using a screening instrument (93.5%, 417/446).

PREDICTORS OF SCREENING

In univariate analyses, the likelihood that oncologists would report screening patients for distress could be predicted by their knowledge of NCCN guidelines ($P = 0.002$), availability of mental health services ($P = 0.002$), years of experience in oncology practice ($P = 0.03$), gender ($P = 0.03$), lack of time ($P = 0.04$), uncertainty about identifying distress ($P < 0.001$), and uncertainty about treatment options ($P < 0.001$). Practice setting, number of patient-care hours per week, and perception that patients were unwilling to discuss distress were not associated with reported screening. With logistic regression, all associated variables in univariate analyses remained independent predictors of screening with the exception of uncertainty about treatment. Odds ratios are summarized in Table 4. Being very familiar with NCCN guidelines was the strongest predictor of screening. This model had a Hosmer and Lemeshow goodness-of-fit test with a $P = 0.48$.

Using a screening instrument was associated with familiarity with NCCN guidelines ($P = 0.01$) and years of experience ($P = 0.02$) in univariate analyses. Practice setting, oncologist gender, number of hours of seeing patients per week, availability of

Table 4**Predictors of Reported Routine Screening**

VARIABLE	OR	95% CI	P VALUE
Women	2.07	1.18–3.64	0.01
Experience, years			
< 10	—	—	—
10–19	2.36	1.35–4.14	0.003
> 20	2.14	1.24–3.69	0.006
Familiarity with NCCN guidelines			
Not at all familiar with guidelines	—	—	—
Only heard of guidelines	1.26	0.77–2.09	NS
Somewhat familiar with guidelines	2.12	1.20–3.73	0.009
Very familiar with guidelines	2.88	1.01–8.26	0.05
Available mental health services	2.21	1.44–3.41	< 0.001
Lack of time	0.55	0.32–0.93	0.02
Uncertainty about identifying distress	0.45	0.28–0.74	0.001

Abbreviations: OR = odds ratio; CI = confidence interval; NCCN = National Comprehensive Cancer Network

mental health services, lack of time, uncertainty in identifying distress, and uncertainty in treating distress were not associated with use of a screening instrument. With logistic regression, those who reported being very familiar with NCCN guidelines had over three times the odds of using a screening instrument (odds ratio [OR] 3.7; 95% CI, 1.5–8.9; $P = 0.004$). Years of experience did not have a monotonic relationship; having 10–19 years of experience remained an independent predictor (OR 2.7; 95% CI, 1.3–5.6; $P = 0.01$). This model had a Hosmer and Lemeshow goodness-of-fit test with a $P = 0.62$.

Discussion

FAMILIARITY WITH NCCN GUIDELINES

Although NCCN guidelines for distress have been available for almost a decade, they do not appear to be widely disseminated among practicing oncologists. One third of oncologists in this study reported that they had not heard of the NCCN guidelines, and only one third reported having some familiarity with the recommendations. This finding was consistent across the oncologists' practice settings, years of experience, and amount of patient contact.

Despite this low rate of familiarity with the NCCN guidelines, two thirds of the oncologists in the sample reported screening patients for distress routinely. Many reported doing so by observing mood; this method, however, has been unreliable, since oncologists frequently miss cues indicating need for emotional support from their patients.¹² Some asked their patients a very direct question, such as, "Are you depressed?" This type of questioning may be very helpful as a quick screen for a major depression, but it fails to capture other forms of emotional distress.¹³ Only 14% of oncologists in our study used a screening instrument that was developed specifically to assist in the recognition of distress. Instead, they inquired about and observed the patient and family's

behavior, mood, and coping skills, integrating this practice into their routine encounters.

Without systematic screening, distress may go unrecognized and untreated. In studies of how oncologists recognize stress in their patients, false-negative rates of 15%–20% have been reported, with up to 50%–94% of cancer patients with psychiatric disorders (eg, depression) left unrecognized.^{2–5} Based upon estimates from previous studies, if we assign a detection rate of 50% to oncologists who do not report routine screening and a detection rate of 100% to those who use a screening instrument, at least 42.5% of patients with distress (14.2% of all cancer patients) currently may experience undetected stress. The recognition of this problem, however, is only one facet of knowing that patients require mental health services; this estimate falls within the range of reported distress rates among patients not receiving treatment.^{14–18}

Greater familiarity with NCCN guidelines is associated with reported routine screening. However, whether this awareness actually leads to screening or oncologists who are already more interested in psychosocial issues have read the NCCN guidelines is unclear. Still, an argument can be made for the former. The Distress Thermometer is included explicitly in the NCCN guidelines; however, few oncologists report using a screening instrument, even though most say that they would consider using an available instrument of this type. The few oncologists who used a screening instrument were more likely to report greater familiarity with NCCN guidelines, but they were just as likely to report uncertainty in identifying and treating distress.

EXPERIENCE, GENDER

Although years of experience and the oncologist's gender were not associated with knowledge of the NCCN guidelines, both were associated with reporting routine screening for distress. One could speculate that oncologists with increased experience encountered more distress and observed its impact on medical management. Alternatively, with more experience, they may have become more efficient in their practices and able to devote some clinical time to psychosocial issues.

Our finding that female oncologists were more likely to report screening is not surprising, given past research. Female physicians are more likely to have a patient-centered communication style and to engage in behaviors to facilitate the reporting of symptoms.^{19,20}

BARRIERS TO SCREENING

Many barriers to screening were reported, yet few actually were associated with reported screening. The pace of clinical practice, with its associated lack of available time, was the most frequently reported barrier to screening for distress; indeed, this barrier was associated with a decreased likelihood to screen patients routinely. The perception that patients are unwilling to discuss distress also was a commonly reported barrier; unfortunately, although this belief may hold true for some patients, it generally is a misconception. In fact, 25% of cancer patients report that they would talk about emotional

issues with their oncologists if only they were asked.²¹ Accordingly, mental health services were cited as a needed resource for screening; availability of such services was an independent predictor of reported routine screening.

Oncologists expressed interest in improving their practices with regard to one barrier—knowledge about identifying distress. Half of the respondents believed that more training in identifying and treating distress would be helpful. However, few oncologists take time off from their busy practices to attend educational sessions to receive that training. Moreover, the effectiveness of these programs in increasing the detection of distress has been questioned.²²

LIMITATIONS

Although this study provided a first look at oncologists' awareness of NCCN guidelines for distress and their practice of screening for the condition, it had several limitations. First, self-reported practice may not reflect what takes place in the clinic accurately. These data may provide a more idealized report of clinical practice, as they may overestimate both awareness and screening rates. Also, the survey focused on "distress," the general term for psychological, social, and/or spiritual difficulties used in NCCN guidelines; it did not ask about such specific psychiatric disorders as major depression and delirium.

Our response rate was similar to or better than those of other large surveys of oncologists about supportive care and communication issues; however, the possibility of bias remained.^{23–25} Were the respondents oncologists who were more interested in psychosocial care? If the respondents were biased, one would expect a higher percentage of oncologists reporting routine screening and familiarity with NCCN guidelines in the samples with lower response rates. However, these rates were very similar in all three stages of the survey (home institution, home state, and nation); each stage had differing

response rates. This observed consistency of reports argued against an obvious bias.

Another limitation of this survey of oncologists was its inability to capture the complexity of multidisciplinary care. Rather than one physician, teams of healthcare professionals often care for oncology patients. Other members of the team might have screened patients for distress without the full awareness of the oncologists. This complexity of care might be reflected in the goodness-of-fit tests for our models, which suggested that even more factors than the ones involved here were involved.

Although the present study may not have been as accurate as a large-scale observational investigation of oncologists' actual behavior would have been, it provided valuable information on what oncologists believe they are doing. No matter what actually happens in their clinical practice, oncologists who believe they are following guidelines will see less need to change their behavior to conform to the recommendations. Data from this study may lay a foundation for future work on interventions to improve the quality of psychosocial care for cancer patients.

Conclusion

Future efforts directed at improving the recognition and treatment of psychosocial distress in oncology settings may benefit from disseminating the NCCN guidelines more widely. Simple awareness of these guidelines was associated with screening in this study, but a previous survey of oncologists found that one of the most important characteristics of clinical guidelines was based upon clinical trials.²⁶ To facilitate the uptake of NCCN guidelines, research must be done on the feasibility of implementing these recommendations and on their impact on outcomes. This research would both strengthen these guidelines and identify obstacles to their practice that may result in revisions.

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