Metastatic Lung Cancer and Distress

Use of the Distress Thermometer for patient assessment

Victoria Sherry, DNP, CRNP-BC, AOCNP®, Carmen Guerra, MD, MSCE, FACP, Anjana Ranganathan, MD, and Susan M. Schneider, PhD, RN, AOCN®, ACNS-BC, FAAN

BACKGROUND: Patients with metastatic lung cancer experience high levels of distress related to their disease trajectory and treatment. Oncology nurses are experts in patient care and symptom management, giving them an opportunity to screen and treat patients’ distress.

OBJECTIVES: The objectives of this study were to screen patients for distress and manage their symptoms to positively affect their quality of life, treatment adherence, and clinical outcomes, and to reduce healthcare costs.

METHODS: This quality improvement project was conducted to pilot the Distress Thermometer (DT) into the care of patients with thoracic cancer and to evaluate the effect of a multifaceted intervention, consisting of a patient education pamphlet and a nurse coaching call, on distress levels.

FINDINGS: Severe distress was reported in more than half the patients. A paired-sample t test revealed a significant decrease in distress scores following the intervention.

BACKGROUND:
Patients with advanced lung cancer have been shown to have a high symptom burden and elevated levels of distress related to their disease (Molassiotis, Lowe, Blackhall, & Lorigan, 2011). The National Comprehensive Cancer Network ([NCCN], 2016) defines distress as a multifactorial unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Undetected distress is associated with decreased quality of life, reduced treatment adherence, poorer clinical outcomes, and increased overall healthcare costs (Molassiotis et al., 2011). Screening for distress in patients with cancer is recommended by the NCCN, Oncology Nursing Society, Commission on Cancer (COC), and the Health and Medicine Division (HMD) of the National Academies of Sciences, Engineering, and Medicine, and many institutions are working to adopt this as a standard practice. The impetus behind distress screening is to improve patient quality of life and positively affect treatment outcomes and survival (Adler & Page, 2008; COC, 2012; Eaton & Tipton, 2009; NCCN, 2016). Patients diagnosed with lung cancer experience physical distress brought on by symptoms of cancer and treatments, as well as financial, spiritual, emotional, and psychosocial distress. Management of patients’ symptoms through education is essential to helping them cope with distress (NCCN, 2016).

The Abramson Cancer Center, a National Cancer Institute (NCI)–designated comprehensive cancer center located in Philadelphia, Pennsylvania, conducted a pilot project to implement distress screening in thoracic oncology. The authors of the current study initiated a systematic method to educate patients about their symptoms to help mitigate distress. This study focused on testing a multifaceted intervention to reduce distress levels in adults with stage IV lung cancer through early screening assessment, patient education, a follow-up coaching telephone call by a nurse, and reassessment of distress.

Background
Lung cancer is the leading cause of cancer-related deaths in men and women worldwide, claiming more than 1.6 million lives each year (Stewart & Wild, 2014). Metastatic non-small cell lung cancer is a devastating disease.
that results in high symptom burden and poor quality of life; the five-year relative survival rate for metastatic lung cancer is 4% (American Cancer Society, 2017; Temel et al., 2010). Fifty percent of all patients with cancer experience some form of distress, but patients with lung cancer represent the highest levels of distress (Carlson, Waller, Groff, & Bultz, 2013; Lowery & Holland, 2011), likely because a significant proportion of patients with lung cancer present with advanced disease that is deemed incurable (Carlson et al., 2013).

Managing distress has been a focus in oncology care. In 2008, the Alliance for Quality Psychosocial Cancer Care formed to implement screening guidelines based on the recommendations of the NCCN and HMD for routine screening and treatment of distress in patients with cancer (Lowery & Holland, 2011). They aimed to recognize distress, with the goal of increasing treatment options, improving outcomes for patients with cancer, and making cancer care more comprehensive (Bultz & Johansen, 2011).

Distress screening is integral to delivering high-quality cancer care. The COC developed standards requiring all cancer centers to implement distress screening into their practice by January 1, 2015 (COC, 2012). These standards mandate screening at least one time during a pivotal medical visit, defined as a clinic visit posing the greatest risk for distress (e.g., time of diagnosis, first day of chemotherapy). The screening tool and method of administration are left to the discretion of the institution. If oncology teams identify moderate to severe distress in their patients, they are responsible for assessing, treating, and referring them to psychosocial services (COC, 2012). The drive to implement distress screening routinely into practice was initiated by the HMD’s landmark report titled Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (Adler & Page, 2008), which endorsed a new quality benchmark that included the integration of the psychosocial domain routinely into cancer care. Despite the recommendations of the NCCN and HMD to implement distress screening for all patients with cancer, early intervention and management of distress remain a challenge.

A variety of tools to measure distress are available. Many of them measure psychological distress and fail to screen for other causes of distress. A review of the literature revealed that the NCCN’s Distress Thermometer (DT) is an inclusive screening tool that evaluates psychosocial symptoms and assesses physical, practical, family, and spiritual/religious symptoms. The DT has been shown to have good reliability and validity, with a sensitivity of 77% and specificity of 66% (Mitchell, 2007). A score of 4 or greater on the DT is considered moderate to severe distress and warrants intervention (NCCN, 2016). Understanding distress scores and symptoms that cause distress can help direct educational interventions and improve patient quality of life.

Patient outcomes are not merely affected by screening for distress. Follow-up intervention to mitigate distress is crucial. Management of symptoms that cause distress through patient education can improve quality of life. Although limited literature assesses the value of patient education for individuals with lung cancer, its effectiveness has been demonstrated in patients with other types of cancer. Lack of patient education about symptom management can have a devastating impact on distress levels and quality of life (Pasacreta, Kenefick, & McCorkle, 2008). Through patient education, advanced practice nurses can facilitate effective coping and reduce distress (Allen, Zebrack, Whittman, Hammelef, & Morris, 2014). Another patient education tool, a nurse coaching call, has not been studied in lung cancer but has had a very promising effect in decreasing distress levels and increasing quality of life in patients with other types of cancer (Black et al., 2014; Schneider, Adams, & Gosselin, 2014; Thomas et al., 2012).

The current study aims were twofold: (a) to pilot distress screening into standard thoracic oncology patient care using the DT and (b) to evaluate the effect of a patient education pamphlet and a coaching call made by a nurse on distress levels in patients with metastatic lung cancer with a distress score of 4 or greater. Secondary aims included evaluating the feasibility of the DT and coaching telephone call.

**Methods**

**Setting and Sample**

The DT, patient education, and coaching call were implemented at the Abramson Cancer Center at the Hospital of the University of Pennsylvania. The thoracic oncology team consists of seven oncologists and six advanced practice providers. Convenience sample inclusion criteria included adults with metastatic lung cancer who were undergoing cancer treatment, could read and write English, were aged older than 21 years, and had a distress level greater than 4 on the DT. The sample size accrual goal was 40 patients who had a distress score greater than 4. Data collection was initiated in August 2015 and completed in December 2015.
2015. The authors screened a total of 92 patients to meet their target of 40 patients with a distress level greater than 4.

Procedures
The institutional review board at the University of Pennsylvania reviewed this study and determined it was a quality improvement project, exempt from review. This study used a systematic approach to distress screening and managing symptoms that cause distress in patients with metastatic lung cancer. Each eligible patient was asked to complete the DT using a tablet computer when arriving at the appointment. The DT is comprised of an overall distress item on which patients rate how much distress they have been experiencing in the previous week, including that day, on a scale of 0 (no distress) to 10 (extreme distress). The DT also asks patients to indicate any problems they experienced in the past week, including that day, on a yes-or-no response scale (http://bit.ly/1i3JedY). Variables measured with the DT include 6 practical problems, 4 family problems, 6 emotional problems, 1 spiritual/religious concern, and 22 physical symptoms (NCCN, 2016). The authors used a cross-sectional approach with individual patients being screened at different phases of treatment, some at the start of first-line therapy, others on second- and third-line therapy, and others not on active therapy. The completed forms were collected by the lead author at the time of the clinic visit.

Any patient with a distress score of 4 or greater received a tailored intervention consisting of an evidence-based patient education pamphlet specific to any problems they noted on the DT, a personalized explanation of how this information may help them, as well as a follow-up coaching call within one to three days to assess the patient’s understanding of the pamphlet and to answer any questions. In addition to tailored patient education, every eligible patient received a pamphlet on oncology resources at Abramson Cancer Center, which provided contact information of professionals who could assist them (i.e., a social worker, nutritionist, and nurse navigator dedicated to thoracic oncology). The coaching call was conducted by the lead author.

To provide reliable delivery of the coaching call intervention, a call script was used as a guide. In addition to managing the reported symptoms, the coach offered referrals to social work, palliative and supportive care services, physical therapy, integrative medicine, financial services, and nutrition, when appropriate. Each patient’s distress was reassessed at the time of his or her next clinic visit, which took place within one to three weeks, depending on the patient’s treatment schedule. Patients were asked to rate their postintervention distress based on the symptoms identified in the DT at the initial screening. The coaching conversations were documented in the patients’ medical records to communicate with other providers. Per guideline recommendations, if a patient presented with a distress score of 7 or greater at either the pre- or postintervention measurement, the project manager immediately contacted a member of the healthcare team, in case the patient required prompt medical attention (NCCN, 2016).

Analysis
A pre-/post-test intervention design was used in this study. The outcome data from the pretest formed the basis for the patient education and coaching call. Descriptive data included gender, age, smoking status, and race. Feasibility data were recorded for the distress screening scale and included the percentage of eligible patients who were screened, time to complete distress screening, and ease of use. Analysis of data from all aims was conducted using SPSS®, version 20.

Findings
Ninety-two eligible patients were successfully screened for distress. Forty-one patients screened met inclusion criteria of a DT score of greater than 4 and were eligible for the distress management intervention. Patient demographic information is presented in Table 1. The majority of patients were female and White. Of the 51 ineligible patients, 47 patients did not meet inclusion criteria and 4 patients refused to participate.

Patients’ distress scores (X = 6.74, SD = 1.37) were measured prior to the intervention. Severe distress was reported in 20 patients. The number of problems reported ranged from 4–24. One individual reported 24 areas of distress; all 41 patients reported at least four symptoms. The most commonly reported symptoms that caused distress were fatigue (n = 35), worry (n = 26), pain and

<table>
<thead>
<tr>
<th>TABLE 1. DISTRESS SCREENING PATIENT CHARACTERISTICS (N = 41)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHARACTERISTIC</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
</tr>
<tr>
<td>Male</td>
<td>12</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>34</td>
</tr>
<tr>
<td>Black or African American</td>
<td>6</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
</tr>
</tbody>
</table>

*One patient self-identified as Hispanic.

Note. All patients had stage IV lung cancer.
nervousness (n = 23), sleep (n = 19), fears (n = 17), and nausea, constipation, and sadness (n = 15).

A paired-sample t test revealed a significant decrease in distress scores from the pre- (X = 6.74, SD = 1.37) to post-test (X = 3.61, SD = 2.79) (t [38] = 6.51, p = 0.00). Two of the patients who completed the DT died and were unable to complete the post-intervention screening.

Most patients (n = 36) reported that the DT was very easy to use and took fewer than five minutes to complete (n = 39). Intervention fidelity was determined by asking patients if they read the patient educational material provided during the coaching call. All patients reported that they had read the education.

Discussion
This pilot project revealed that a tailored educational intervention and coaching call can decrease distress in patients with metastatic lung cancer. The authors demonstrated that screening for distress with the DT in an outpatient thoracic oncology clinic was feasible. In a three-month period, the authors were easily able to administer the DT to 92 individuals and identify patients at risk for distress (n = 41). The demographic data revealed that 29 participants were female, perhaps implying that women have higher levels of distress or that they are more likely to report distress compared to men (Linden, Vodermaier, MacKenzie, & Greig, 2012). Psychosocial, physical, practical, family, and spiritual/religious symptoms all were documented as sources of distress in this patient population. More than two-thirds of the patients rated their distress as severe, confirming the high acuity and complexity of patients with metastatic lung cancer and highlighting the importance of using a comprehensive tool when screening for distress. The findings are consistent with those of Carlson et al. (2013), who reported that 51% of patients with lung cancer reported high levels of distress.

The decision of the authors to screen patients for distress using a cross-sectional approach was based on the NCCN (2016) guidelines for distress management, which recommend screening patients at various times. The findings of the current study reveal that distress is present throughout the treatment trajectory. Although this study screened individual patients only once, for feasibility training, screening should occur periodically during the course of treatment so that any changes in the degree and cause of distress do not go unrecognized and untreated. This concept has been reinforced in a quality improvement project conducted by Hammelof, Friese, Breslin, Riba, and Schneider (2014), who found that patients with repeated screenings were more amenable to accepting services to mitigate distress.

The findings from the current study support the work of Allen et al. (2014), who advocated for patient education by advanced practice nurses to facilitate effective coping and reduce distress. In addition to patient education pamphlets, coaching calls helped mitigate distress levels in patients with metastatic lung cancer. The patient education pamphlets addressed all patient-reported symptoms, and the coaching calls allowed the authors to focus on one or two of the most distressing symptoms. For example, when a patient reported elevated distress levels because of high medication co-payments, the nurse coach suggested that the patient enroll in a cost-saving pharmacy plan at the institution and provided related information. Another patient’s distress stemmed from losing her hair from chemotherapy. She was given a prescription for a cranial prosthesis, directed to a boutique that sold wigs, and enrolled in a local Look Good Feel Better program. In addition, one patient who noted he was experiencing changes in appetite and was unable to maintain weight despite taking an appetite stimulant was given samples of a protein supplement and a prescription that was filled at a discounted price at the institution. This tailored approach contributed to the successful management of distress.

Finally, the follow-up coaching calls were feasible to implement and generally of short duration (mean time of 6.85 minutes per call), allowing for all patient questions regarding the education pamphlets to be answered. Most participants were reached in one or two telephone calls. The current findings are comparable to those of other studies (Black et al., 2014; Schneider et al., 2014; Thomas et al., 2012) that demonstrated success with coaching calls made by nurses to support patients and manage symptoms. The use of a coaching call script promotes the replicability of the intervention by oncology nurses in other settings. Patient satisfaction with the innovation was not measured formally; however, most patients reported that the patient information pamphlets and coaching call were informative and personalized.

Limitations
Limitations of this project included the small, predominantly female sample and that it was performed at a single site with patients with metastatic lung cancer; outcomes may not be generalizable to other oncology settings, diseases, or stages. In addition, the follow-up DT scores were determined by the overall DT rating; the authors did not collect specific symptom data at the second measure. Last, the authors did not have follow-up data on the proportion of patients who received referrals to supportive services to determine if they had used them.

Conclusion
Patients with metastatic lung cancer experience a high degree of distress related to treatment and the disease process. Screening
and managing distress are key components of providing quality oncology nursing care; however, in busy oncology practices, they can be overlooked. Fortunately, when distress is identified and treated, patients no longer feel that they need to endure it.

Oncology nurses are at the forefront of patient care and have a unique opportunity to significantly affect patients’ quality of life and outcomes through nurse-led distress screening and management intervention. This study demonstrated that oncology nurses can implement distress screening, manage symptoms through evidence-based education, follow up with a coaching call, and facilitate appropriate referrals to help relieve patient distress. The innovation of this nurse-led project can be used in other oncology specialties to deliver individualized care that addresses patients’ psychosocial, physical, practical, family, and spiritual/religious needs across the treatment continuum.

Victoria Sherry, DNP, CRNP-BC, AOCNP®, is an oncology nurse practitioner in Thoracic Malignancies at the Abramson Cancer Center at the Hospital of the University of Pennsylvania, Carmen Guerra, MD, MSCE, FACP, is an associate professor in the Perelman School of Medicine at the University of Pennsylvania; and Anjana Ranganathan, MD, is an assistant professor of clinical medicine in the Department of Hematology and Oncology at the Hospital of the University of Pennsylvania, all in Philadelphia; and Susan M. Schneider, PhD, RN, AOCN®, ACNS-BC, FAAN, is an associate professor in the School of Nursing at Duke University in Durham, NC. Sherry can be reached at victoria.sherry@uphs.upenn.edu, with copy to CJONEditor@ons.org. (Submitted March 2016. Accepted September 16, 2016.)

The authors gratefully acknowledge Caregive Systems for providing the tablet computer for the Distress Thermometer screening.

The authors take full responsibility for this content. This study was funded, in part, by a grant from the American Cancer Society and an ONS Foundation clinical doctoral scholarship awarded to Victoria Sherry. The article has been reviewed by independent peer reviewers to ensure that it is objective and free from bias.

REFERENCES