Numerous articles have demonstrated that patients undergoing treatment for cancer experience distress. Research has also shown that patients whose distress is effectively identified and treated may tolerate their chemotherapy better and have improved quality of life. Oncology nurses at the Lowell General Hospital Cancer Center, through their participation in the Breast Cancer Care Measures portion of the ONS Foundation–supported Breast Cancer Quality Measures Set pilot and the Oncology Quality Collaborative, identified that the distress assessment used at their institution was ineffective. The assessment tool did not identify the reason for the patient’s distress and therefore was ineffective at triggering appropriate interventions needed for resolution of the patient’s distress. The following article highlights the process by which the Lowell General Hospital Cancer Center implemented a new distress assessment tool and uses a patient case study to illustrate its effectiveness.

Susanne Huberty, MSN, FNP, AOCNP®, is an oncology nurse practitioner and Monica Buckley, RN, MSN, OCN®, is an oncology nurse educator, both at Lowell General Hospital Cancer Center in Massachusetts. The authors take full responsibility for the content of the article. The authors received editorial support from Kristen Fessele, PhD, RN, AOCN®, in preparation of this article funded by a grant to the ONS Foundation from the Breast Cancer Fund of the National Philanthropic Trust. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the independent peer reviewers or editorial staff. Huberty can be reached at susanne_tighe@hotmail.com, with copy to editor at CJONeditor@ons.org. (Submitted April 2014. Revision submitted June 2014. Accepted for publication June 10, 2014.)

Key words: distress; symptom assessment; chemotherapy

Digital Object Identifier: 10.1188/14.CJON.S2.45-48

The diagnosis of cancer can cause physical, emotional, and social distress (National Cancer Institute, 2012). Patients who employ the use of effective coping strategies have been shown to have fewer symptoms as a result of their cancer treatment, in addition to lower levels of depression and anxiety (Gaston-Johansson, Haisfield-Wolfe, Reddick, Goldstein, & Lawal, 2013; National Cancer Institute, 2012; Zabalegui, 1999). Patients who have their distress identified and treated may tolerate their chemotherapy better and improve their quality of life compared to patients who do not (Lev et al., 2001; Sarna, 1998). The current article illustrates the process by which the Lowell General Hospital (LGH) Cancer Center implemented a new distress assessment tool and highlights a patient example of how the tool was used successfully.

Pilot Project

Level of distress was one of the key measures being studied by the LGH Cancer Center as a participant in the ONS Foundation-supported Breast Cancer Care (BCC) Quality Measures Set pilot study. Members of the LGH nursing staff performed chart reviews on all patients with breast cancer who received their first chemotherapy treatment from January to June 2009. Data were collected for the first six months of their treatment or until treatment was completed, whichever occurred first. All of the charts reviewed had documented assessment of distress after diagnosis and prior to the first chemotherapy treatment from January to June 2009. Data were collected for the first six months of their treatment or until treatment was completed, whichever occurred first. All of the charts reviewed had documented assessment of distress after diagnosis and prior to the first chemotherapy treatment. The reviewed charts also demonstrated that staff members were reassessing the patient’s level of distress at least one time during each chemotherapy cycle. When the charts were reviewed for a documented intervention for distress, 86% had a narrative note illustrating some form of intervention given to the patients.

Process

Because of LGH’s participation in the BCC Measures pilot study, it was invited to participate in a new phase of the project called the Oncology Quality Collaborative, supported by the ONS Foundation. LGH was 1 of 15 hospitals across the country participating in an initiative aimed at evaluating and
implementing methods to improve quality measure scores in symptom assessment.

The first meeting of the Oncology Quality Collaborative took place on December 13, 2011, in Pittsburgh, PA. Through networking with oncology nurses from all over the United States and listening to expert speakers lecture on the topic of symptom assessment, it became clear to the participants from LGH that their distress assessment was lacking. Although LGH’s distress assessment scores were high, the nurses participating in the project did not feel that the psychosocial assessment tool used was helping to identify the specific stressors that patients were experiencing. The tool, which was simply a check box format completed by the RN, was focused on the patient’s affect. It did not identify whether the patient’s distress was because of chemotherapy side effects, financial difficulties, or family challenges.

The proposed revision of the existing distress tool was brought to the medical oncology unit-based council meeting on March 29, 2012. The Oncology Nursing Society’s Putting Evidence Into Practice resource had a list of various clinical measurement tools that could be used to assess anxiety (Eaton & Tipton, 2009). These tools were located using the Internet and brought to the council meeting for review. At the April 26, 2012, meeting of the unit-based council, a decision was made to initiate a process by which LGH’s medical oncology department would use the National Comprehensive Cancer Network (NCCN) Screening Tools for Measuring Distress to assess distress moving forward. The Distress Thermometer was decided on for its simplicity, as well as for the fact that it addressed the specific practical, emotional, and physical problems that patients experience while undergoing treatment for cancer (NCCN, 2014) (see Figure 1).

At the July 26, 2012, meeting of the unit-based council, pivotal time points to administer the scale were decided. The patients would be given the NCCN Distress Thermometer to complete at their chemotherapy teaching session, at their last chemotherapy session, and anytime their chemotherapy regimen was changed, including when it was changed for disease progression. Patients scoring a 3 or less would be given the business card of the social worker. If the patient scored a 4 or greater, a social worker would contact the patient within 48 hours. The nurse would be responsible for ensuring that the social work team was notified of any patient scoring a 4 or higher on the scale.

**FIGURE 1. Distress Thermometer Screening Tool**

*Note.* Reproduced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.1.2011. © 2010 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines® and illustrations herein may not be reproduced in any form for any purpose without the express written permission of the NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. NATIONAL COMPREHENSIVE CANCER NETWORK®, NCCN®, NCCN GUIDELINES®, and all other NCCN Content are trademarks owned by the National Comprehensive Cancer Network, Inc.
Although the Distress Thermometer technically is self-administered by the patient, the nurse is instrumental in not only explaining how to complete the tool, but conveying its purpose and how the patient’s responses will be addressed. The patient must feel comfortable sharing his or her fears and personal life details with the nurse reviewing the tool, which is often difficult at the initial teaching session. While acknowledging the personal nature of the information provided, the nurse must promote trust and support the patient.

The Distress Thermometer was administered at all pivotal time points beginning on August 15, 2012. A year later, on September 5, 2013, the distress tool became part of the chart review done by the quality initiative team.

Case Study

D.G. was a 42-year-old single mother of two children, an adult son aged 23 years and an 11-year-old daughter. She cleaned houses to financially support her family. After a 2–3 week history of pelvic discomfort and rectal bleeding, she was sent for a colonoscopy. D.G. was found to have extensive neoplastic involvement of her rectum. Her lumen was so narrowed that a complete colonoscopy could not be performed. She was sent for an urgent oncology consult on the same day as her colonoscopy.

After seeing her oncologist, D.G. was sent for a positron emission tomography (PET) scan, which showed intensive uptake spanning 12 cm of her rectum, consistent with her known rectal cancer. It also demonstrated uptake within a lymph node in her perirectal fat, indicating that the cancer was not contained within her rectum. Even more concerning was a broad area of fluoro-deoxyglucose accumulation in her right colon near her hepatic flexure, which suggested that D.G. might have an additional area of cancer in her colon. The radiologist performing the PET scan recommended direct visualization by colonoscopy. However, the patient was unable to have a colonoscopy performed because her gastroenterologist was unable to advance the colonoscope beyond her rectal mass.

The patient underwent concurrent chemoradiation with a continuous infusion of 5-fluourouracil for six weeks. She then underwent a low anterior resection and choanal anastomosis. A colonoscopy was performed after her surgery and found multiple polyps, at least 20, ranging in size from 5 mm to 1.5 cm. D.G.’s gastroenterologist told D.G. that the colonoscopy findings were very suggestive of a genetic disorder.

When D.G. arrived at LGH Cancer Center, the staff had begun administering the Distress Thermometer as the new distress assessment tool that very same day. After D.G. had received education regarding the chemotherapy regimen she would be receiving as adjuvant therapy (folinic acid, fluorouracil, and oxaliplatin [FOLFOX]), she was asked to complete the Distress Thermometer. D.G. scored an 8 on a scale of 0–10 on the thermometer. The patient checked off areas of difficulty in the “practical problems,” “emotional problems,” and “physical problems” areas of the tool.

Because D.G. scored an 8 on the Distress Thermometer, she was contacted by a social worker within 48 hours. For “practical problems,” the patient had checked off that she was having difficulty with “insurance/financial.” Because of the intense treatment that the patient had already received, including a long surgical recovery period, she had been able to work very little. She was the sole provider to her family and was having trouble paying her bills. As her treatment with FOLFOX progressed, she developed severe neuropathy in her hands and feet despite multiple interventions, making work even more difficult.

Because D.G.’s financial need was identified by the new distress assessment tool, she began a series of meetings with a financial member of the social work team. She was given a grant from the LGH fundraising initiative to help her pay some bills. The medical oncology staff members also adopted D.G.’s family for the holidays; they collected money and gift cards for D.G. so that she could shop for herself and her children. The social work team helped D.G. to apply for social security and, when it was denied, to apply for an appeal.

The patient had also checked off difficulty with “treatment decisions.” D.G. admitted that she had increasing anxiety regarding upcoming treatment. She had been told by her surgeon that she would need another surgery and that he was unsure whether or not her colostomy would be able to be reversed. The patient wanted to have the colostomy reversed and had a lot of anxiety over the possibility that it may not be able to be done. The patient also admitted uncertainty regarding the significance of the multiple polyps found during her colonoscopy. She was worried about whether or not she had a genetic disorder. Finally, she admitted to a lot of uncertainty regarding her earlier PET scan findings. The PET scan was suggestive of the fact that she could have colon cancer as well as rectal cancer. In addition, the patient checked off “depression,” “fears,” “nervousness,” “sadness,” “worry,” and “loss of interest in usual activities” on the emotional problem portion of the distress tool. The patient began regular counseling with a member of the social work team who specialized in counseling. In addition, she was seen by a member of the nurse practitioner staff, who started the patient on an antidepressant.

Finally, the patient checked off “eating,” “fatigue,” “sleep,” and “pain” as problems under the physical problem portion of the tool. Through regular meetings with the nurse practitioner and social worker, it was determined that all of these physical problems were likely manifestations of the severe depression she was experiencing. Several weeks after the antidepressant and counseling had started, documented improvement was shown in the patient’s chart in all of the physical problems.

Additional Treatment

D.G. received 12 cycles of adjuvant FOLFOX. She had a genetic assessment done that showed a mutation in the APC gene.

<table>
<thead>
<tr>
<th>Implications for Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incorporate an effective symptom assessment tool to identify specific stressors for patients undergoing treatment for cancer experiencing generalized distress.</td>
</tr>
<tr>
<td>Improve a patient’s quality of life and his or her tolerance to chemotherapy through the use of distress assessment tools.</td>
</tr>
<tr>
<td>Use distress assessment tools to identify patient and family needs.</td>
</tr>
</tbody>
</table>
The mutation was a deletion of Exon 1-15. In addition to her colorectal cancer risk, the patient was told that she also had a 5%–12% risk of duodenal and periampullary cancer. Because of the patient’s genetic findings, she underwent a panproctocolectomy. Despite her strong desire to have her colostomy reversed, D.G. retained a permanent colostomy.

D.G. was left with severe neuropathy in her hands and feet because of the severe treatment she underwent. The patient was unable to wear socks on her feet and was unable to resume the house cleaning she had done previously. After an appeal was completed by the social work department, D.G. was finally granted social security. The patient continues close medical supervision with her oncologist and continues to receive counseling in the social work department.

If D.G. had presented to LGH Cancer Center a month earlier than she had, she would not have been administered the NCCN Distress Thermometer tool. She would have likely been referred to social work simply if she had demonstrated any signs of distress. Because the Distress Thermometer had been administered, the nursing and social work team were able to identify the patient’s specific needs, and address them accordingly. The patient’s care truly involved a multidisciplinary approach. She was seen regularly by four physicians in different specialties: medical oncology, radiation oncology, gastroenterology, and surgery. Her care team also included nursing (her infusion room nurse and a nurse practitioner) and a three-person social work team that guided her through financial roadblocks, as well as provided support through counseling. With continued use of the NCCN Distress Thermometer, LGH has been able to help more patients than just D.G. The LGH Cancer Center has increased the number of patient referrals to the social work department and has also directly improved the nurses’ ability to provide quality care to their patients.

Conclusion

The assessment of specific stressors experienced by patients with cancer have a direct effect on the quality of life and care of the patient undergoing chemotherapy. By identifying specific emotional, physical, and practical problems at key points during the patient’s illness, appropriate interventions can be initiated and addressed in a timely manner, improving the patient’s quality of life and his or her overall tolerance to treatment. Use of a distress assessment tool can effectively guide and assist the oncology nurse in providing high quality, holistic, patient-centered care.

The authors gratefully acknowledge Theresa Camacho, RN, BSN, OCN®, Gloria Langlois, RN, OCN®, and Anne Paparello, RN, BSN, for the time and effort that was devoted to the Breast Cancer Quality Measures Project data collection. The authors also thank the medical oncology unit–based council for its dedication and support of this project and for the role that the council played in implementing the new distress assessment process. Finally, the authors thank D.G. for letting them tell her story. Her selfless wish to help others, after the difficult struggle that she endured, is an inspiration to oncology patients and the oncology nurses who care for them everywhere.

References


