# Setting the Bar: Developing Quality Measures and Education Programs to Define Evidence-Based, Patient-Centered, High-Quality Care

Kristen Fessele, PhD, RN, AOCN®, Susan Yendro, RN, MSN, and Gail Mallory, PhD, RN, NEA-BC



In 2008, the Oncology Nursing Society (ONS) initiated a multi-year project to develop and test quality measures in areas judged by oncology nurses as high-priority opportunities to improve quality of life for patients across the cancer continuum, and to provide education to oncology nurses on how to achieve high-quality care. Supported through a grant to the ONS Foundation by the Breast Cancer Fund of the National Philanthropic Trust, two teams of expert nurses convened to review the literature and draft potential measures that are considered important to providers and patients, are high-volume, high-impact issues, and are supported by strong clinical evidence linking high-quality care processes to improved outcomes. The ONS Foundation contracted with the Joint Commission's Department of Quality

Measurement to combine its measure-development experience with ONS's ambulatory oncology perspective to create a reproducible testing process. A third project team designed and implemented a series of 10 regional education workshops illustrating the use and benefits of quality measurement in clinical care.

Kristen Fessele, PhD, RN, AOCN®, is a postdoctoral fellow in the College of Nursing at the University of Utah in Salt Lake City; Susan Yendro, RN, MSN, is an associate project director in the Department of Quality Measurement at the Joint Commission in Oakbrook Terrace, IL; and Gail Mallory, PhD, RN, NEA-BC, is the director of research at the Oncology Nursing Society (ONS) in Pittsburgh, PA. The authors take full responsibility for the content of the article. This article was supported 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. The views expressed in this article are those of the authors and do not reflect the official policy or position of ONS. Fessele can be reached at kristen.fessele@nurs.utah.edu, with copy to editor at CJONEditor@ons.org. (Submitted April 2014. Revision submitted June 2014. Accepted for publication June 8, 2014.)

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ecent emphasis on improving quality in health care, as part of the Affordable Care Act, has placed a strong focus on performance measurement (Centers for Medicare and Medicaid Services, 2013). Many reasons exist to participate in nationally benchmarked quality-measurement programs, such as to achieve or maintain accreditation, maintain or improve reimbursement, or demonstrate excellence. Many strong performance measurement programs exist, such as American Society of Clinical Oncology's ([ASCO's], 2014) Quality Oncology Practice Initiative and the American Nurses Association's ([ANA's], 2014) National Database for Nursing Quality Indicators. Oncology quality metrics frequently focus on aspects of cancer screening, diagnostic work-up, and the initiation of appropriate anticancer treatments, with very few focusing on patient-centered measures. In 2008, the Oncology Nursing Society (ONS), a professional organization

of more than 35,000 RNs and other healthcare providers, initiated a multi-year project to develop and test two sets of quality measures for patient-centered topics (primarily symptoms) with interventions supported by high-level research evidence in the ONS (2014) Putting Evidence Into Practice (PEP®) resources. The topics selected by oncology nurses were those with high-priority opportunities to improve quality of life and quality of care for patients across the cancer continuum, and to complement those measures already in existence.

Teams of expert oncology nurses convened to review the literature and draft potential measures that are considered important to providers and patients, are high-volume, high-impact issues, and are supported by strong clinical evidence linking high-quality care processes to improved outcomes. The ONS Foundation contracted with the Joint Commission's Department of Quality Measurement to combine its established

TABLE 1. Breast Cancer Care (BCC) Quality Measures Set and Aggregate Rates

Identification	Title	Aggregate Rate (%)
BCC-01a	Pretreatment Assessment: Overall Rate	33.27
BCC-01b	Pretreatment Assessment: Distress	75.93
BCC-01c	Pretreatment Assessment: Fatigue	64.5
BCC-01d	Pretreatment Assessment: Sleep-Wake Disturbance	37.17
BCC-02a	Continuing Assessment: Overall Rate	19.85
BCC-02b	Continuing Assessment: Distress	55.55
BCC-02c	Continuing Assessment: Fatigue	62.07
BCC-02d	Continuing Assessment: Sleep-Wake Disturbance	27.03
BCC-03	Intervention for Psychosocial Distress	32.14
BCC-04	Intervention for Fatigue: Exercise Recommendation	9.79
BCC-05	Intervention for Sleep-Wake Disturbances	12.36
BCC-06	Assessment of Chemotherapy-Induced Nausea and Vomiting	87.41
BCC-07	Education on Neutropenia Precautions	55.82
BCC-08	Granulocyte—Colony-Stimulating Factors Prescribed	76.26

and rigorous, but primarily inpatient, measure-development experience with a more varied and potentially less structured ambulatory oncology environment. A goal of the project was to create a reproducible process for measure development, and this was achieved and demonstrated through testing in 2010 of the ONS Foundation-supported Breast Cancer Care (BCC) Quality Measures Set for people in active treatment, followed in 2012 by the ONS Foundation-supported Breast Cancer Survivorship (BCS) Quality Measures Set for people one year after completion of treatment (see Tables 1 and 2).

# Measure Development Process

The final sets of measures were selected after a broad outreach to solicit comments from ONS members, interdisciplinary clinicians, and patient advocacy stakeholder groups. The comments were used to review, revise, or clarify the measures where indicated. An invitation was concurrently issued to clinical practice sites providing care to patients with breast cancer to apply to participate as a pilot site in a validity and reliability testing project. More than 100 clinical practices applied to participate; the final pilot site samples were selected through a statistical process, ensuring a balance of varied characteristics. Diversity among factors such as practice type and ownership (e.g., government,

physician, or corporate owned; freestanding or hospital outpatient department), geographic region in the United States, teaching and National Cancer Institute-designation status, and level of urbanization at the practice location were sought to assess reliable measure performance regardless of the setting. Each selected pilot site completed a business associate agreement or a Data Use Agreement and was approved by the pilot site's institutional review board where requested.

The 18-month measure development and testing process is outlined in Figure 1. Key to the design of quality measures suitable for national benchmarking are steps to ensure that the instruments perform in a valid and reliable manner whether used in a large, urban academic center or a rural physician practice. The "alpha" phase of testing included project staff making four visits to pilot sites to conduct in-depth reviews of the newly drafted measure specification manual, which detailed the instructions used to abstract the appropriate data elements for each patient case. Site participants discussed their perceptions of the manual's directions, and ambiguous language was flagged for revision. Subsequent data collection and management training sessions were conducted for all sites via webinar, and a four-month abstraction and submission period commenced.

Twelve site visits were conducted at the conclusion of the BCC and BCS pilot study data collection periods, where project staff re-abstracted patient case data, and the responses were immediately compared to those originally submitted. The Joint Commission developed this rapid comparison process to facilitate robust discussion among project staff and site participants when discordant values were noted to uncover remaining ambiguities in the collection instruction language prior to final manual revision.

# The Quality Measures

The BCC Measures, which focus on aspects of the care of the patient with stages I-IV disease receiving IV chemotherapy, were tested in 39 pilot sites. The measures provided feedback regarding the consistency with which the practice assesses symptoms (e.g., fatigue, nausea and vomiting, psychosocial distress, sleepwake disturbances) throughout the course of chemotherapy as well as with documentation of interventions for clinically significant levels of these problems (those judged to be moderate to severe, regardless of specific rating tool used). In the case of cancer-related fatigue, a measure was developed to examine the percentage of patients starting a chemotherapy regimen who received a recommendation to exercise. Exercise has been shown through randomized, clinical trials and meta-analyses as an effective intervention for fatigue, as well as other important patient outcomes, such as depression, anxiety, lymphedema, and sleep-wake disturbances (ONS, 2014; Schmitz et al, 2010). The national aggregate score for this measure was less than 10%, indicating a significant gap in care to be addressed.

The BCC Measures also explore the consistency with which patients and family members are educated regarding hand hygiene and the specific degree of fever that should generate a call to the oncology practice for those at risk of febrile neutropenia (FN). The final measure evaluates whether white blood cell-colony-stimulating factors are prescribed for patients receiving chemotherapy regimens with published rates of FN greater than

20% (Smith et al., 2006). Although the aggregate score for this measure was relatively high, onsite project staff re-abstraction of a portion of the total submitted cases during reliability testing of this measure indicated difficulty with and variances across pilot sites in identifying FN rates for all possible dosing regimens. This affected consistent identification of denominator cases. At the time of writing, this measure is recommended for local quality-improvement use only, rather than for potential national benchmarking purposes.

The BCS Measures explore the care of patients with earlystage breast cancer in the 12-month period after multimodality definitive therapy is completed; eligible patients may continue with postchemotherapy trastuzumab, tamoxifen, or aromatase inhibitor use. The measures set was tested in 42 pilot sites in 2012. Because cancer- and treatment-related symptoms may persist, in some cases, for years after therapy ends (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Shi et al, 2011), the first two measures seek evidence of continued assessment of and intervention for clinically significant levels of the symptoms noted in the BCC Measures (e.g., fatigue, psychosocial distress, sleep-wake disturbances) as well as pain, bone health, menopausal symptoms, peripheral neuropathy, and lymphedema, depending on the treatment received by the patient. Modeled, in part, on PEP recommendations summarizing the strength of the evidence for psycho-educational interventions and those from the Institute of Medicine's report From Cancer Patient to Cancer Survivor: Lost in Transition (Hewitt, Greenfield, & Stovall, 2006), the BCS-03 measure looks for documentation of education at the conclusion of treatment related to lymphedema risk, diet and exercise (to support attainment and maintenance of desirable body mass index [BMI] as well as for bone health), available community resources, and signs and symptoms of late effects or disease recurrence to report.

The concept of patient engagement, where patients are consulted, involved in, and share leadership and decision making with their healthcare team (Carman et al., 2013), was operationalized in the BCS-04 and BCS-05 measures. These measures sought documentation that post-treatment health-related goals (e.g., smoking cessation, attainment of a healthy BMI) were selected and supported in collaboration with the patient's desires, rather than in a prescriptive, unilaterally directed manner by the clinician. The project team acknowledged that documentation of this type of discussion may be challenging to locate in the medical records, but feedback from public comment and the pilot sites strongly indicated the importance of retaining and refining these measures. Aggregated scores illustrated less than 20% of patient cases included documentation of collaborative goal setting; of those that did set a goal, 75% made progress toward or completely achieved that goal during the 12-month follow-up period.

BCS-06, Follow-Up Care, evaluates whether the patient received indicated breast imaging, ejection fraction assessment (if still receiving trastuzumab), or a pelvic examination (if on tamoxifen). Because care, such as breast imaging and pelvic examinations, may be overseen by primary or gynecologic healthcare providers, a data element seeking documentation of coordination of care is included as a component of the measure. As currently structured, the coordination of care element minimally requires that collaborating providers be copied on

TABLE 2. Breast Cancer Survivorship (BCS) Quality Measures Set and Aggregate Rates

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Identification	Title	Aggregate Rate (%)		
BCS-01a	Symptom Assessment: Composite Rate	5.2		
BCS-01b	Symptom Assessment: Bone Health Risk	57.76		
BCS-01c	Symptom Assessment: Fatigue	60.1		
BCS-01d	Symptom Assessment: Lymphedema	58.93		
BCS-01e	Symptom Assessment: Menopausal	65.82		
BCS-01f	Symptom Assessment: Neuropathy	57.16		
BCS-01g	Symptom Assessment: Pain	80.75		
BCS-01h	Symptom Assessment: Psychosocial Distress	40.5		
BCS-01i	Symptom Assessment: Sleep	22.96		
BCS-02a	Symptom Intervention: Composite Rate	1.81		
BCS-02b	Symptom Intervention: Bone Health Risk	18.7		
BCS-02c	Symptom Intervention: Fatigue	9.6		
BCS-02d	Symptom Intervention: Lymphedema	14.98		
BCS-02e	Symptom Intervention: Menopausal	25.76		
BCS-02f	Symptom Intervention: Neuropathy	15.52		
BCS-02g	Symptom Intervention: Pain	36.3		
BCS-02h	Symptom Intervention: Psychosocial Distress	11.9		
BCS-02i	Symptom Intervention: Sleep	5.37		
BCS-03a	Post-Treatment Education: Composite Rate	3.87		
BCS-03b	Post-Treatment Education: Community Resources	15.2		
BCS-03c	Post-Treatment Education: Diet	17.88		
BCS-03d	Post-Treatment Education: Exercise	19.79		
BCS-03e	Post-Treatment Education: Late Effects	25.03		
BCS-03f	Post-Treatment Education: Lymphedema	24.16		
BCS-03g	Post-Treatment Education: Recurrence	26.74		
BCS-04	Patient-Engaged Goal Setting	18.64		
BCS-05	Goal Attainment	75.4		
BCS-06a	Follow-Up Care: Composite Rate	70.21		
BCS-06b	Follow-Up Care: Breast Imaging	91.95		
BCS-06c	Follow-Up Care: Coordination of Care	91.3		
BCS-06d	Follow-Up Care: LVEF Assessment	79.07		
BCS-06e	Follow-Up Care: Pelvic Exam	40.29		
BCS-07	Fatigue Improvement	6.08		
BCS-08	Psychosocial Distress Improvement	3.86		
LVEF—left ventricular ejection fraction				



FIGURE 1. 18-Month Process for the Development and Testing of Oncology Nursing Society Quality Measures

visit notes; future work will seek to strengthen this critical area through the identification of additional essential elements.

Two patient-reported outcome measures were tested as part of the BCS set. Fatigue and psychosocial distress have been noted to persist for years post-treatment (Bower et al., 2006; Hodgkinson et al., 2007), and measures BCS-07 and BCS-08 were designed to assess long-term symptom improvement among patients who reported moderate to severe fatigue or psychosocial distress at the time of treatment completion, when compared to the end of the 12-month follow-up period. Patients still experiencing bothersome symptoms one year post-treatment represent a particularly challenging, but important, population. The availability of ongoing outcomes data to a clinical practice on how well patients are recovering from therapy is a critical value-based metric.

# Dissemination of Results and Related Projects

At the conclusion of measures testing, results were disseminated by a number of methods. Project staff presented overall results and lessons learned through poster and podium presentations at several national meetings in 2011 and 2012, including the ONS Congress and Connections conferences, the 2012 ASCO Quality Care Symposium, and the 2012 ANA Quality Conference. On a local level, pilot sites received a score report indicating the organization's percentage rate for each measure, as well as the nationally aggregated rate across all participating sites. After receiving the BCC Measures score reports, several site coordinators asked for guidance on how to improve suboptimal performance areas, initially seeking tools and best practices in use by high-performing organizations within the pilot group. To create a communication platform to allow free exchange of ideas and concerns, ONS created the Oncology Quality Collaborative (OQC) in 2011, a community of practice model (Wenger & Snyder, 2000) that allows interested pilot site participants to meet via a monthly conference call to discuss issues related to symptom management, survivorship care, and other practice topics.

One objective achieved by the OQC was to use the BCC Measures a second time in 2012 to capture changes in performance after implementation of practice changes designed in response to the initial 2010 testing. Nine sites submitted data on 226 patient cases for a subset of BCC assessment-focused measures, and notable improvements in scores were achieved overall, highlighting the value of repeated use of quality measures for audit and feedback as part of a continuous quality-improvement process (see Table 3).

In 2012, a major educational goal of the grant was achieved through the design and implementation of a series of 10 regional workshops focused on the use of quality measurement to improve oncology nursing care. ONS members (N = 352) attended the three-hour sessions, and workshop evaluations indicated that 97% of attendees felt they met their personal goals for attending the program. Many participants noted that they improved their understanding about how the quality-improvement process relates to patient outcomes and that they felt better equipped to use quality measures in their practices. Several attendees appreciated the clinical scenario woven throughout the workshop,

# **Implications for Practice**

- Ensure that measures focus on issues relevant to oncology nursing practice because healthcare reform efforts focus on the need to demonstrate high-quality, high-value cancer care
- Derive quality measures intended for use in national reporting programs from a strong evidence base, and ensure that those measures demonstrate validity and reliability for use across diverse practice settings; pilot testing is essential.
- Promote a culture of high-quality care in organizations through awareness of and participation in quality-measurement and quality-improvement efforts.

TABLE 3. Breast Cancer Care (BCC) Quality Measures Set 2012 Re-Abstraction Summary With Aggregate Rates

Identification	Title	Aggregate Rate (%)
BCC-01a	Pretreatment Assessment: Overall Rate	44.25
BCC-01b	Pretreatment Assessment: Distress	74.34
BCC-01c	Pretreatment Assessment: Fatigue	77.88
BCC-01d	Pretreatment Assessment: Sleep-Wake Disturbance	51.77
BCC-02a	Continuing Assessment: Overall Rate	39.38
BCC-02b	Continuing Assessment: Distress	65.04
BCC-02c	Continuing Assessment: Fatigue	86.73
BCC-02d	Continuing Assessment:Sleep-Wake Disturbance	54.42
BCC-04	Intervention for Fatigue: Exercise Recommendations	23.98
BCC-06	Assessment for Chemotherapy-Induced Nausea and Vomiting	92.73

which focused on the rationale for and implementation of the BCC-04 measure recommending exercise for patients receiving chemotherapy as an intervention to manage fatigue. Participants felt that the information and symptom assessment tools illustrated in the program could be applied directly to their practice. To assess long-term outcomes of the workshops, attendees received a survey six months after the program. Twenty-five percent (n = 76) of the participants responded, and 62 of the respondents reported that they shared information learned with colleagues, 27 made personal changes in their clinical practice, and 13 began to collect or use existing quality data (Lillington et al., 2013).

## Conclusions

The multiple components of this quality-measurement project (i.e., developing and testing breast cancer quality measures; national, regional, and local presentations; regional quality education; publications; and the OQC) supported by the National Philanthropic Trust Breast Cancer Fund grant to the ONS Foundation enabled ONS to translate strong evidence-based practice resources, such as PEP, into tools that can be used in any oncology clinical practice to identify areas for quality improvement. Oncology nurses gravitate to the specialty to provide the highest quality cancer care to patients. It often is difficult to pinpoint areas that can benefit most from practice change without the ability to examine the consistency with which critical care processes and outcomes are achieved. Future work will continue to focus on areas most important to oncology nurses, patients, and caregivers to strive for a culture of quality in every setting, every day.

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