Evaluating the Quality of Supportive Oncology Using Patient-Reported Data

By Sydney M. Dy, MS, MSc, Anne M. Walling, MD, PHD, Jennifer W. Mack, MD, MPH, Jennifer L. Malin, MD, PhD, Philip Pantoja, MA, Karl A. Lorenz, MD, MSHS, and Diana M. Tisnado, PhD

Johns Hopkins Bloomberg School of Public Health, Baltimore, MD; University of California, Los Angeles; Veterans Health Administration of Greater Los Angeles, Los Angeles, CA; and Dana-Farber Cancer Institute, Boston, MA

Abstract

Purpose: Patient-reported data may provide valuable information for oncology quality measurement. We evaluated applying patient-reported data from the Cancer Care Outcomes Research and Surveillance Consortium national study to quality indicators addressing supportive oncology domains.

Methods: We analyzed surveys including validated instruments for symptoms and care planning from 4,174 patients newly diagnosed with lung or colorectal cancer. We adapted existing supportive oncology indicators for use with patient-reported data from Cancer Quality-ASSIST and the American Society of Clinical Oncology Quality Oncology Practice Initiative. Where feasible, we examined indicators using medical record data for comparison purposes.

Results: Using patient-reported data, the percentage of patients meeting indicator criteria for screening ranged from 74% (significant depressive symptoms) to 93% (pain, nausea/vomiting).

The percentage meeting indicator criteria for symptom treatment ranged from 73% (significant depressive symptoms) to 99% (nausea/vomiting). Symptom severity did not affect the results. Using medical record data, the percentage meeting indicator criteria varied between 4% (significant depressive symptoms) and 23% (pain). For information and care planning, 44% met criteria for discussion about resuscitation and 32% for hospice discussion using survey data. Using medical record data, 11% met criteria for goals-of-care discussion in intensive care and 46% for hospice/pain management/palliative care referral before death.

Conclusion: Quality of care for symptoms measured using patient self-report was higher than when including medical record data. Use of patient-reported and medical record data allowed measurement of different perspectives on care planning indicators. Patient-reported data provide a complementary, patient-centered perspective on the quality of supportive oncology care.

Introduction

Quality indicators for supportive oncology are critical for measuring and monitoring improvement in patient-centered domains such as symptom management and communication.¹ Most indicators developed for these domains use medical record abstraction. The evidence-based Cancer Quality-ASSIST (Assessing Symptoms Side Effects and Indicators of Supportive Treatment) quality indicators, in use in regional and national quality measurement projects, address domains including information and care planning and symptoms such as pain and dyspnea.² The American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI), a voluntary practice-based quality measurement and benchmarking program widely used in the United States, includes a number of indicators in the domains of symptom management and end-of-life care.³ The National Quality Forum has endorsed selected measures from both of these sets.⁴

Although medical records are an important data source, the patient perspective is also critical to include in quality measurement, because patients are the best reporters of their own experiences. Patient-reported data on issues such as current symptoms could complement medical record documentation in assessing quality, particularly for care that occurs across providers and settings. For example, it may be impractical to use

medical records to assess quality if patients see multiple clinicians over multiple settings without integrated health records. Patient-reported data can also provide information on issues not documented in medical records, such as the impact of pain on patients and patients' perspectives on quality of care. However, quality indicators based on information obtained directly from patients also have limitations. Patient expectations of care may affect reports as much as what actually occurs (eg, satisfaction with pain management), and patients may be unable to compare care they are receiving with accepted standards or may not be aware of deficits in care. Ongoing research is evaluating how best to incorporate patient-reported data into medical records and databases useful for quality measurement and research, such as registries.^{5,6} However, although a few quality indicators based on these data are endorsed or in current use,⁷ such indicators have not yet been developed or implemented for oncology patients.

To evaluate how patient-reported data collected in clinical practice might be used in quality indicators for key supportive oncology domains (symptoms and information and care planning), we conducted a study modeling this approach using patient-reported data from the national Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) cohort. First, we adapted supportive oncology quality indicators for use

with existing patient-reported data; second, we applied these indicators to describe the quality of supportive oncology care using the patient perspective; and third, we described how performance of indicators measured using patient-reported data compared with those using medical record documentation in this data set.

Methods

Quality Indicator Sets

We reviewed key quality indicator sets developed in the United States that include tested indicators relevant to supportive oncology and palliative care in domains included in the CanCORS patient survey data, focusing particularly on those endorsed by the National Quality Forum.⁴ National Quality Forum endorsement focuses on the domains of importance, inter-rater reliability, basis in measure concepts that are associated with quality outcomes, feasibility, and variation in performance. Domains included symptom screening (ie, assessing presence of symptoms), symptom treatment, and information and care planning (eg, discussions about hospice care and timely goals of care discussions). The Cancer Quality-ASSIST project addresses both outpatient and hospital care in supportive oncology domains, including pain, dyspnea, fatigue, nausea/vomiting, depression, and information and care planning.⁸ The ASCO QOPI addresses many of the same domains, including symptom indicators focusing on the end of life and hospice admissions.^{3,9}

CanCORS Survey

The CanCORS initiative was a national US study of health care and outcomes of > 10,000 patients diagnosed with lung or colorectal cancer from 2003 to 2005.¹⁰ Survey and medical record data collection occurred in five regions, including Alabama, Iowa, northern and southern California, and North Carolina, and included five integrated health care delivery systems and 10 Veterans Administration hospitals. Details of the survey development and data collection have been described elsewhere.¹¹ For this study, we included 4,174 individuals with both a full baseline survey and medical record data who responded to the Quality of Life/Symptoms, Supportive Care, and Goals of Treatment and Prognosis sections of the survey (cohort characteristics listed in Table 1).

The survey assessed patient sociodemographic characteristics and experiences with care, including a detailed assessment of symptom screening and management. It also assessed the presence of symptoms in the past 4 weeks and symptom severity using validated instruments. These included the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ) questions for nausea/vomiting, dyspnea, cough, and diarrhea; the Short Form 36 (SF-36) vitality scale for fatigue¹²; the Center for Epidemiologic Studies Depression Scale (CES-D-8)¹³ for depressive symptoms; and the Brief Pain Inventory (BPI) for pain. Questions related to dyspnea were asked of patients with lung cancer. Patients who

Table 1. Study Population Demographic and Clinical Characteristics (N = 4,174)

Characteristic	No.	%
Sex		
Male	2,315	55.5
Female	1,859	44.5
Age, years		
21 to 59	1,363	32.65
60 to 69	1,244	29.80
70 to 79	1,111	26.62
≥ 80	456	10.92
Race/ethnicity		
White	3,035	72.7
Black	546	13.1
Hispanic or Latino	210	5.0
Other	383	9.2
Cancer type		
Lung	1,894	45.4
Colorectal	2,280	54.6
Extent of disease, stage		
I to III	3,231	77.4
IV	943	22.6
Marital status		
Married	2,461	59.0
Other	1,713	41.0
Education		
< High school	683	16.4
High school/vocational school/some college	2,472	59.2
≥ College degree	1,014	24.3
Refused/do not know/missing	5	0.1
Annual household income		
< \$20,000	1,150	27.6
\$20,000 to < \$40,000	1,122	26.9
\$40,000 to < \$60,000	675	16.2
≥ \$60,000	935	22.4
Refused/do not know/missing	292	7.0
Insurance type		
VA	614	14.7
Private	1,386	33.2
Supplemental	1,575	37.7
Public	438	10.5
None	146	3.5
Missing	15	0.4

NOTE. The median time from diagnosis to baseline interview was 4.2 months (interquartile range, 2.0 months).

Abbreviations: IQR, interquartile range; VA, Veterans Administration.

reported having each symptom were also asked whether the physician knew about the symptom, whether they wanted help from the physician for the symptom, and, if yes, whether they had received help. To assess patients' experiences with information and care planning, the survey queried whether they had ever discussed resuscitation or hospice with a physician.

Adapting Quality Indicators for CanCORS Data

We first identified indicators using Cancer Quality-ASSIST, the indicator set developed specifically for supportive oncology, that could be adapted for use with the CanCORS survey data. For domains that were addressed in CanCORS but did not correlate with Cancer Quality-ASSIST indicators, we reviewed published measure descriptions from ASCO QOPI³ and other relevant indicator sets^{14,15} and selected those for which we could most closely match indicator descriptions with CanCORS data. Finally, we reviewed the CanCORS survey to identify potential indicators that did not correlate directly to specified indicators in these sets but corresponded to the domains of symptom management and information and care planning. The final set of indicators is listed in Tables 2 and 3.

Symptom Management Quality Indicators

For symptom domain quality indicators, we adapted indicators for symptom screening and treatment for five key symptoms: pain, dyspnea, fatigue, nausea/vomiting, and depression (details provided in Appendix Table A1, online only). For each symptom, we adapted the existing indicators for symptom screening to be operationalized using the survey question: "Does your doctor know about your SYMPTOM." For comparison purposes, we created medical record versions of these indicators that addressed whether the presence of the symptom in question was documented in at least one physician visit in the medical record in the prior 4 weeks. Because of the survey skip pattern, patients were only asked this question if they had reported that they had the symptom. Therefore, for the survey and medical record versions to be parallel, we used the same denominator of patients who reported having the symptom according to the survey data.

For symptom treatment, original indicators evaluated whether, if a symptom was significant, severe, or worsening, there was a change in the treatment plan or documentation of a reason for no change in plan. We were able to operationalize these indicators only with the patient-reported data, not with the medical record data collected in CanCORS. We adapted the indicators for use with the survey questions by including whether patients reported that they had received the help they wanted for that symptom from their physician. To operationalize the quality indicators for symptoms where severity was part of the indicator definition (all except depression; Table 2), we evaluated the indicators with all patients and performed sensitivity analysis for moderate to severe symptoms.

Because the symptom survey items asked about symptoms and treatment during the previous 28 days, we only included patients in the denominator who had a cancer-related outpatient physician visit within 28 days before the survey. For fatigue, to correspond with the eligibility specifications of this indicator, we included only patients receiving chemotherapy within the 28-day time period. For dyspnea, because indicators referred to patients with advanced lung cancer at the very end of life, we included only those with stage IV disease who had completed the survey within 2 months of death (more details on

adaptation of symptom indicators provided in Appendix Table A1, online only).

Information and Care Planning

The information and care planning quality indicators are listed in Table 3. For the survey versions of information and care planning indicators addressing hospice, we used the survey item: "Did any doctor or other health care provider recommend hospice care for you?" For care planning, we used the item: "Has a doctor ever talked to you about whether you would want to be revived or use life-sustaining machines?" To be consistent with the timeframe addressed by the QOPI measure and the intent of the corresponding ASSIST quality indicator, these item denominators were restricted to patients with stage IV disease who completed the survey within 2 months of death to capture patients at the end of life. Finally, we were able to adapt three additional indicators from Cancer Quality-ASSIST in this domain for use with the CanCORS medical record data in those with stage IV disease: whether patients who died received palliative care, pain management, or hospice before death and whether patients had a documented goals-of-care discussion within 3 days of admission to the intensive care unit or after being placed on mechanical ventilation.

Data Analysis

We conducted descriptive analyses to determine how well each indicator could be specified using CanCORS patient self-reported data, to describe performance with each indicator, and to qualitatively compare performance on different types of indicators and different symptoms and domains. For each indicator, we developed detailed specifications and calculated the percentage of survey respondents eligible for the indicator, numerators (number of respondents receiving specified care), denominators (number of respondents eligible for each indicator), and the percentage of respondents receiving care as specified by the indicator (numerator divided by denominator). For selected indicators, we also performed sensitivity analyses to determine the impact of alternative specifications on indicator performance. Data analyses for this article were performed using SAS software (version 9.3; SAS Institute, Cary, NC). This study was approved by the Veterans Health Administration Institutional Review Board and was conducted in accordance with an assurance filed with and approved by the US Department of Health and Human Services.

Results

In this full cohort of patients eligible for these indicators (N = 4,174), 45% had lung and 55% had colorectal cancer; 23% had advanced-stage disease. Approximately 56% were men, 73% were white, and 67% were age ≥ 60 years. Sixteen percent had less than a high school education, and 28% had an annual household income $< \$20,000$ (Table 1).

For symptom domains using survey data only, the percentage of patients reporting meeting criteria for recommended screening ranged from 74% for significant depressive symptoms

Table 2. Indicator Results: Symptoms

Domain/Indicator*	Eligible Patients		Pass Rate†		Indicator Adapted From
	No.	Denominator (%)	No.	Numerator (%)	
Survey-based indicators					
Pain (N = 4,174)					
Screening: if patient with cancer-related outpatient visit reports having pain, then patient should report that physician knows about pain	1,138	27.3	1,061	93.2	ASSIST: patients with cancer-related visits should have been screened for pain (related QOPI indicator)
Treatment: if patient with cancer-related outpatient visit reports both having and wanting help for pain, then patient should report that physician provided help for pain	763	18.3	696	91.2	ASSIST: patients should have received treatment for pain (related QOPI indicator)
Nausea/vomiting (n = 389)‡					
Screening: if patient with advanced cancer affecting GI tract or abdomen has cancer-related outpatient visit and reports having nausea and/or vomiting, then patient should report that physician knows about nausea and/or vomiting	105	27.0	98	93.3	ASSIST screening for nausea/vomiting (only patients with stage IV colorectal cancer)
Treatment: If patient with advanced cancer affecting GI tract or abdomen has cancer-related outpatient visit, and both has and reports wanting help for nausea and/or vomiting, then patient should report that physician provided help for nausea and/or vomiting	75	19.3	74	98.7	ASSIST indicator on treatment for nausea/vomiting
Fatigue (N = 4,174)					
If patient with cancer patient has cancer-related outpatient visit while undergoing chemotherapy and reports having fatigue, then patient should report that physician knows about fatigue	853	20.4	775	90.9	ASSIST indicator on screening for fatigue
Treatment: if patient with cancer has cancer-related outpatient visit while undergoing chemotherapy and reports wanting help for fatigue, then patient should report that physician provided help for fatigue	412	9.9	317	76.9	Modeled on similar measure for pain
Dyspnea (n = 554)					
If patient with advanced lung cancer with cancer-related outpatient visit reports having dyspnea, then patient should report that physician knows about dyspnea	26	53.1	23	88.5	QOPI indicator on dyspnea documentation on last two visits before death for patients with advanced lung cancer (stage IV only) who died within 2 months of baseline survey (similar indicator in ACOVE)
Treatment: if patient with lung cancer with cancer-related outpatient visit reports having and wanting help for dyspnea, then patient should report that physician provided help for dyspnea	14	28.6	13	92.9	QOPI indicator; dyspnea addressed before death of patients (stage IV only) who died within 2 months of baseline survey
Significant depressive symptoms (N = 4,174)					
If patient with cancer with cancer-related outpatient visit reports having significant depressive symptoms, then patient should report that physician knows about depressive symptoms	352	8.4	260	73.9	ASSIST indicator on depression screening after cancer diagnosis; only significant depressive symptoms included (CES-D-8 score ≥ 6) to correspond with following indicator
Treatment: if patient with cancer with cancer-related outpatient visit and significant depressive symptoms reports wanting help for depressive symptoms, then patient should report that physician provided help for depressive symptoms	174	4.2	127	73.0	ASSIST indicator on treatment after diagnosis of depression; defined as significant depressive symptoms in survey (CES-D-8 score ≥ 6)
Medical record–based indicators§					
Pain (N = 4,174)					
Screening: If patient with cancer-related outpatient visit reports having pain, then pain should be documented in medical record	1,138	27.3	265	23.3	ASSIST indicator on pain
Nausea/vomiting (n = 389)					
Screening: If patient with advanced cancer with cancer affecting GI tract or abdomen has cancer-related outpatient visit and reports having nausea and/or vomiting, then nausea and/or vomiting should be documented in medical record	105	27.0	17	16.2	ASSIST indicator on nausea/vomiting
Fatigue (N = 4,174)					
If patient with cancer has cancer-related outpatient visit while undergoing chemotherapy and reports having fatigue, then fatigue should be documented in medical record	853	20.4	122	14.3	ASSIST indicator on fatigue
Continued on next page					

Continued on next page

Table 2. (Continued)

Domain/Indicator*	Eligible Patients		Pass Rate†		Indicator Adapted From
	No.	Denominator (%)	No.	Numerator (%)	
Dyspnea (n = 49)					
If patient with advanced lung cancer with cancer-related outpatient visit reports having dyspnea within last 2 months of life, then dyspnea should be documented in medical record	26	53.1	6	23.1	QOPI indicator on dyspnea documentation at end of life
Significant depressive symptoms (N = 4,174)					
If patient with cancer with cancer-related outpatient visit reports having significant depressive symptoms, then depression should be documented in medical record	352	8.4	14	4.0	ASSIST indicator on depression screening

NOTE. Measures based on measure descriptions but do not use actual measure specifications.

Abbreviations: ACOVE, Assessing Care of Vulnerable Elders; ASSIST, Cancer Quality–Assessing Symptoms Side Effects and Indicators of Supportive Treatment; CES-D-8, Center for Epidemiologic Studies Depression Scale; QOPI, Quality Oncology Practice Initiative.

* All apply to 28-day period before survey.

† Pass rates similar for moderate to severe symptoms for both medical record and survey indicators (eg, 28.8% for pain screening for survey compared with 27.3%; numbers small for many symptoms).

‡ Questions related to nausea and those related to vomiting were combined.

§ Physicians' visits evaluated only for medical record–based indicators.

to 93% for pain and nausea/vomiting. For treatment, the percentages ranged from 77% for fatigue and 73% for significant depressive symptoms to 99% for nausea/vomiting. In sensitivity analyses, varying the inclusion criteria for the indicators based on symptom severity did not markedly affect performance on the quality indicators (eg, 93.2% when including all patients with pain compared with 94.5% when including only moderate to severe pain; Table 2). For the symptom domains

using survey and medical record data, the percentage of patients who reported that they had a symptom within the last 4 weeks on the survey and had this documented in a physician note during that time period ranged from 4.0% to 23.3%. Limiting these indicators to those with moderate to severe symptom severity again generally did not change results appreciably (eg, 29.1% for those with moderate to severe pain compared with 23.3% for all those reporting pain).

Table 3. Indicator Results: Information and Care Planning

Domain/Indicator (n = 943)	Eligible Patients		Pass Rate		Indicator Adapted From
	No.	Denominator (%)	No.	Numerator (%)	
Survey-Based Indicators					
If patient with advanced cancer dies expected death, then there should have been discussion of hospice before death	63*	6.7	20	31.8	QOPI indicator on discussion within 2 months of death; ASSIST indicator on expected death (advanced cancer; although this addressed referral, which could not be discerned from CanCORS data); patients with stage IV disease who completed survey within 2 months of death
If patient with advanced cancer dies expected death, then patient should report that provider had discussed patient preferences for resuscitation and life support†	63*	6.7	28	44.4	ASSIST indicator on documentation of advance directive for patients (stage IV only) who died within 2 months of baseline survey
Medical Record–Based Indicators					
If patient with advanced cancer dies expected death, then patient should have been referred to palliative care before death (hospital-based palliative care or pain management or community hospice)	799	84.7	369	46.2	ASSIST indicator on hospice or palliative care; CanCORS medical record data measure discussions, referrals, and visits and also include pain management with palliative care
If patient with advanced cancer is admitted to ICU and survives 3 days, then within 3 days of ICU admission, medical record should document that patient preferences for care have been considered	91	9.7	10	11.0	ASSIST indicator; similar results for 14 days
If patient with advanced cancer requires mechanical ventilation, within 3 days of initiation of mechanical ventilation, medical record should document goals of care and patient preferences for mechanical ventilation	20	2.1	7	35.0	ASSIST indicator

Abbreviations: ASSIST, Cancer Quality–Assessing Symptoms Side Effects and Indicators of Supportive Treatment; CanCORS, Cancer Care Outcomes Research and Surveillance Consortium; ICU, intensive care unit; QOPI, Quality Oncology Practice Initiative.

* No. is much lower for survey data because data were only collected once; hence, requirement that patient die within 2 months after baseline survey, as in QOPI. For medical record indicator, because medical record data were collected over time, this 2-month requirement was not necessary.

‡ Survey question: “Has a doctor ever talked to you about whether you would want to be revived or use life-sustaining machines?”

For the domain of information and care planning and indicators using survey data, 44% met criteria for discussion about resuscitation and 32% for discussion about hospice. For indicators using medical record data, 46% met criteria for a discussion, referral, or visit to palliative care, pain management, or hospice; 11% met criteria for discussion of preferences if admitted to intensive care; and 35% met criteria for discussion of preferences after receiving mechanical ventilation (Table 3).

Discussion

In this study, we successfully adapted a number of medical record–based supportive oncology and end-of-life quality indicators from Cancer Quality-ASSIST and QOPI to patient-reported data using the national CanCORS survey of patients with lung or colorectal cancer. In data from this cohort study, performance on screening indicators was much higher on indicators using patient-reported data as compared with medical record data, although the indicators were specified somewhat differently. The percentage of respondents reporting receiving recommended care as specified by the patient-reported indicators was twice as high for the domains of symptom screening and treatment as compared with information and care planning, with three quarters to nearly all patients reporting recommended care for symptoms and only one third to one half for care planning. Rates were also higher for symptoms that were more objective or where more effective treatments exist (eg, pain, nausea/vomiting) compared with more subjective (eg, fatigue, significant depressive symptoms). The percentage of patients reporting receiving recommended care for screening and treatment indicators was relatively similar within each symptom.

Only a small number of these medical record–based indicators could be measured using patient-reported survey data, and these required many adaptations. Given the one-time, cross-sectional nature of the survey (which would likely be the case in clinical practice as well), certain denominators needed to be respecified to address care within appropriate time windows around the survey, such as limiting the hospice indicator from QOPI to patients who died within 2 months of survey administration. Rather than relating to a specific visit, symptom items related to a 1-month time period before survey administration. Concepts were parallel but reflected the provision of care somewhat differently (eg, for symptom screening, medical record indicator would reflect documentation of symptom in physician's note only within the last month; these survey indicators reflected patient self-report that their physician knew about their symptom). Symptom indicators were adapted to a patient-reported perspective rather than to physician-reported diagnoses; for example, rather than a physician diagnosis of depression (where documentation would often not include description of how diagnosis was obtained), indicators were adapted to address patient-reported significant depressive symptoms on a validated scale. Rather than address the need for treatment by symptom severity, the survey-based indicators addressed patient-perceived need (ie, whether patient wanted help for symptom).

Performance was much higher for the patient-reported data screening indicators, as constructed in this study, than for indicators using medical record data both in this study and in other studies using only medical record data from Cancer Quality-ASSIST¹⁶ and QOPI.¹⁷ These differences demonstrate the potential value of collecting patient-reported data as part of quality assessment. Most patients reported the belief that the physician knew about their pain; however, for those who had a physician visit within the last month and had self-reported pain within that time period, it was usually not documented in the medical record. Here, a patient's report can give a more global assessment of care than assessing a single visit with the medical record and can also define moderate to severe symptoms not found in the record. Some of these differences reflect the differences in perspective, as we have described—physicians' perceptions and documentation compared with patients' perceptions of what their provider is aware of or patient-perceived needs—and some reflect the wording of survey items (eg, whether patient ever had discussion about resuscitation with physician, compared with whether this was done as part of his or her oncology care). The medical record portions of the indicators are important to document what care was actually received and to determine quality of care attributable to specific providers.

Study strengths include the national survey sample in a variety of settings, diverse population, and use of validated survey instruments, but this study also has a number of limitations. The survey was not specifically designed for quality indicators, limiting which quality indicators we could measure; this required us to adapt the existing quality indicators that we measured. Survey and medical record indicators had some differences, and medical record indicators could not be operationalized in this data set for some domains. Although we made a number of adaptations to fit indicators to existing survey data, results were robust to several sensitivity analyses, with variations in the definitions depending on type of indicator (time period, symptom severity, cancer type, definition of cancer-related outpatient visit). Finally, it is important to note that this study was based on data from a cohort study rather than from routine data collection in oncology clinical practice, which is how these data would likely be collected for quality measurement. This study serves as an initial template of what measure specifications could include using patient-reported data collection, but measure performance may be different using data actually collected in clinical practice.

In summary, we successfully adapted a number of supportive oncology medical record–based quality indicators to patient-reported survey data. These indicators can provide a complementary perspective to medical record–based indicators, with some differences in constructs, such as measuring need for symptom management by the patient's perception of need rather than the severity of the symptom. Administering one-time patient surveys can provide valuable information on quality of care in this population¹⁸ and could also be useful where medical record indicators are less practical, such as in measuring care crossing providers or settings or where resource constraints limit medical record abstraction. Further evaluation of patient-

reported data use with more targeted survey instruments and with routine collection in clinical practice would help elucidate the best use of surveys in quality measurement and measure performance in the clinical setting. Additional perspectives without parallels in medical record indicators could also be useful, such as patient perceptions of communication, as well as different approaches, such as patient-reported data corresponding to specific provider visits. Finally, practical methods to collect patient-reported data at the point of care are needed to make these types of measures possible.

Acknowledgment

Supported by the American Cancer Society. Presented at the American Society of Clinical Oncology Quality Care Symposium, San Diego, CA, November 30-December 1, 2012.

Authors' Disclosures of Potential Conflicts of Interest

Although all authors completed the disclosure declaration, the following author(s) and/or an author's immediate family member(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a "U" are those for which no compensation was received; those relationships marked with a "C" were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of

interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

Employment or Leadership Position: Jennifer L. Malin, Wellpoint (C) **Consultant or Advisory Role:** Karl A. Lorenz, Otsuka Pharmaceutical (C) **Stock Ownership:** Jennifer L. Malin, Wellpoint **Honoraria:** None **Research Funding:** None **Expert Testimony:** None **Patents, Royalties, and Licenses:** None **Other Remuneration:** None

Author Contributions

Conception and design: Sydney M. Dy, Anne M. Walling, Jennifer W. Mack, Jennifer L. Malin, Karl A. Lorenz

Financial support: Jennifer L. Malin

Collection and assembly of data: Jennifer L. Malin, Philip Pantoja

Data analysis and interpretation: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Sydney M. Dy, MS, MSc, Room 609, 624 N. Broadway, Baltimore, MD; e-mail: sdy@jhsph.edu.

DOI: 10.1200/JOP.2013.001237; published online ahead of print at jop.ascopubs.org on March 11, 2014.

References

- Hewitt M, Simone JV: Ensuring Quality Cancer Care. Washington, DC, National Academies Press, 1999
- Dy SM, Lorenz KA, O'Neill SM, et al: Cancer quality-ASSIST supportive oncology quality indicator set: Feasibility, reliability, and validity testing. *Cancer* 116:3267-3275, 2010
- Campion FX, Larson LR, Kadluek PJ, et al: Advancing performance measurement in oncology: Quality oncology practice initiative participation and quality outcomes. *J Oncol Pract* 7:31s-35s, 2011 (suppl)
- National Quality Forum: Palliative and end-of-life care performance measures. http://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx
- Jones JB, Snyder CF, Wu AW: Issues in the design of internet-based systems for collecting patient-reported outcomes. *Qual Life Res* 16:1407-1417, 2007
- Gilbert JE, Howell D, King S, et al: Quality improvement in cancer symptom assessment and control: The Provincial Palliative Care Integration Project (PPCIP). *J Pain Symptom Manage* 43:663-678, 2012
- National Quality Forum: Patient reported outcomes in performance measurement. http://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx
- Lorenz KA, Dy SM, Naeim A, et al: Quality measures for supportive cancer care: The cancer quality-ASSIST project. *J Pain Symptom Manage* 37:943-964, 2009
- American Society of Clinical Oncology: The Quality Oncology Practice Initiative: Review methodology and measures. <http://qopi.asco.org/Methodology.htm>
- Ayanian JZ, Chrischilles EA, Fletcher RH, et al: Understanding cancer treatment and outcomes: The Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 22:2992-2996, 2004
- Malin JL, Ko C, Ayanian JZ, et al: Understanding cancer patients' experience and outcomes: Development and pilot study of the Cancer Care Outcomes Research and Surveillance patient survey. *Support Care Cancer* 14:837-848, 2006
- Barsevick AM, Cleeland CS, Manning DC, et al: ASCPRO recommendations for the assessment of fatigue as an outcome in clinical trials. *J Pain Symptom Manage* 39:1086-1099, 2010
- Turvey CL, Wallace RB, Herzog R: A revised CES-D measure of depressive symptoms and a DSM-based measure of major depressive episodes in the elderly. *Int Psychogeriatr* 11:139-148, 1999
- Hanson LC, Scheunemann LP, Zimmerman S, et al: The PEACE project review of clinical instruments for hospice and palliative care. *J Palliat Med* 13:1253-1260, 2010
- Lorenz KA, Rosenfeld K, Wenger N: Quality indicators for palliative and end-of-life care in vulnerable elders. *J Am Geriatr Soc* 55:S318-S326, 2007 (suppl 2)
- Malin JL, O'Neill SM, Asch SM, et al: Quality of supportive care for patients with advanced cancer in a VA medical center. *J Palliat Med* 14:573-577, 2011
- McNiff KK, Neuss MN, Jacobson JO, et al: Measuring supportive care in medical oncology practice: Lessons learned from the Quality Oncology Practice Initiative. *J Clin Oncol* 26:3832-3837, 2008
- Teno JM, Lima JC, Lyons KD: Cancer patient assessment and reports of excellence: Reliability and validity of advanced cancer patient perceptions of the quality of care. *J Clin Oncol* 27:1621-1626, 2009

Appendix

Table A1. ASSIST and QOPI Symptom Indicators and Adaptation to CanCORS: Example for Pain

Symptom: Pain	ASSIST Medical Record Indicator	QOPI Medical Record Indicator	Appropriate CanCORS Questions*	Adapted Patient-Reported Survey-Based Indicator
Screening	If patient with cancer has cancer-related outpatient visit or is admitted to hospital, then there should be screening for presence or absence and intensity of pain	Pain assessed by second office visit	"Does your doctor know about your pain?"	If patient with cancer-related outpatient visit reports having pain, then patient should report that physician knows about pain
Treatment	If patient has severe sustained or worsening cancer pain or adverse effects, then there should be change in pain regimen or documentation of why pain regimen was not changed	Plan of care for moderate/severe pain documented	"During the last 4 weeks, did you want help for your pain?" "During the last 4 weeks, did you get the help you wanted from your doctor for your PAIN?"	If patient with cancer-related outpatient visit reports both having and wanting help for pain, then patient should report that physician provided help for pain

Abbreviations: ASSIST, Cancer Quality–Assessing Symptoms Side Effects and Indicators of Supportive Treatment; CanCORS, Cancer Care Outcomes Research and Surveillance Consortium; QOPI, Quality Oncology Practice Initiative.

* Questions asked for patients reporting pain or receiving treatments or medications for pain.