Using the American College of Surgeons Cancer Registry to Drive Quality

By Stephen B. Edge, MD, FACS, Daniel McKellar, MD, FACS, and Andrew K. Stewart, MS

Roswell Park Cancer Institute, University at Buffalo, Buffalo, NY; Wright State University, Dayton, OH; and Commission on Cancer, American College of Surgeons, Chicago, IL

Improving the quality of cancer care is a national imperative.¹ There is clear evidence of variations in care that may affect quality, outcomes, and cost of care.²⁻⁵ This may reflect a failure to administer the most effective treatment as well as uncertainty regarding what the most effective treatment is.

To improve quality, we need community-wide commitment of providers, health systems, payers, and the public as well as clear standards and measures of care. There must be mechanisms for constructive feedback to providers and the means to report quality findings to payers and the public.

Quality efforts also require accurate information regarding who has cancer, how they are treated, and what their outcome is. There is no single source of community-wide treatment information. However, unlike all other chronic diseases, large-scale registries have been collecting information on diagnosis, stage, and treatment on almost all Americans with cancer for decades. The concept of a disease registry dates to Ernest Codman, a Boston surgeon early in the last century who pioneered the concept that a hospital should monitor the end results of every patient it treats.⁶ Cancer registries have matured so that they are now a key source of information on patterns and quality of care, care tracking and coordination, and comparative effectiveness.

The United States has three national cancer registry programs. Every state maintains a cancer registry, supported in part by the Centers for Disease Control's National Program of Cancer Registries. The National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program collects more detailed information on patients with cancer in select regions of the country and is designed to provide a population cross-section. Reporting cancer cases to state registries and SEER is legislatively mandated so those registries include all residents diagnosed with cancer in the state or SEER region.⁷⁻⁸ Given that they were primarily designed to study cancer incidence and mortality, these registries have relatively limited treatment information, which makes them of limited value in studying quality.

The other national system is the aggregate of hospital registry data from cancer programs accredited by the Commission on Cancer (CoC) of the American College of Surgeons. The CoC accredits more than 1,500 programs that collectively treat more than 70% of all patients with in the United States. Accredited programs meet organizational and quality standards and maintain a registry of all patients who are diagnosed and/or

receive initial cancer treatment in that program. The registry includes initial cancer stage and treatment data as well as annual follow-up data and vital status. Each program submits its registry data annually for aggregation into a single registry called the National Cancer Data Base (NCDB). The NCDB includes more than 1 million new cases annually in addition to follow-up on the 29 million cases entered previously. In contrast to the population registries, hospital registries have more granular treatment and follow-up information.

Use of the NCDB for Evaluation of Quality of Care

The primary use of the NCDB has been retrospective evaluation of care. The large number of cases allows for robust evaluation of practice and outcomes in common cancers and for the study of rare cancers with numbers of cases that are often an order of magnitude greater than institution-based series.⁹⁻¹⁵ The NCDB may also be used to study disparities and to direct policy. One study conducted by the American Cancer Society demonstrated that patients who lacked health insurance had a poorer outcome with any stage of cancer compared with patients with private insurance.^{10,11,16,17} A bibliography of the more than 350 NCDB publications is at <http://www.facs.org/cancer/ncdb/biblclin.html>. Although the NCDB was only available to a limited number of trained researchers in the past, the CoC recently established a participant user file that allows any investigator at a CoC-accredited program to conduct research using the NCDB. Information related to these participant user files is available at <http://www.facs.org/cancer/ncdb/participantuserfiles.html>.

Quality Measurement

In the last decade, the CoC has actively worked to respond to the Institute of Medicine report¹ by leveraging the cancer registries at its accredited programs for quality monitoring and reporting. The NCDB provides its programs with tools to evaluate patterns of care and unadjusted survival outcomes. On a public Web site, the NCDB reports data summarizing program resources and services available at each center. The cancer center may also choose to include case volume information by stage and cancer type; approximately 80% of CoC-accredited programs provide these data to the public.

In 2005, the CoC developed a set of quality measures for breast and colorectal cancer that could be measured from cancer

Select Breast & Colorectal Measures	Estimated Performance Rates (click rate for comparisons)							Case Review
	2004	2005	2006	2007	2008	2009	2010	
B R E A S T	Radiation therapy is administered within 1 year (365 days) of diagnosis for women under age 70 receiving breast conserving surgery for breast cancer. [BCS/RT]							BCS
	96.8%	96.3%	94.5%	93.2%	93.8%	95.1%	95.1%	
	Combination chemotherapy is considered or administered within 4 months (120 days) of diagnosis for women under 70 with AJCC T1c N0 M0, or Stage II or III ER+ and PR+ negative breast cancer. [MAC]							MAC
	88.6%	97.2%	93.5%	87.2%	77.5%	87.5%	94.1%	
	Tamoxifen or third generation aromatase inhibitor is considered or administered within 1 year (365 days) of diagnosis for women with AJCC T1c N0 M0, or Stage II or III ER+ and/or PR+ positive breast cancer. [HT]							HT
	93.7%	93%	93.3%	94.7%	93.4%	97.6%	98.1%	
C O L O N	Adjuvant chemotherapy is considered or administered within 4 months (120 days) of diagnosis for patients under the age of 80 with AJCC Stage III (lymph node positive) colon cancer. [ACT]							ACT
	100%	100%	87.5%	100%	96%	100%	100%	
	At least 12 regional lymph nodes are removed and pathologically examined for resected colon cancer. [12RLN]							12 RLN
	76%	95.2%	90%	90.9%	100%	100%	100%	
R E C	Radiation therapy is considered or administered within 6 months (180 days) of diagnosis for patients under the age of 80 with clinical or pathologic AJCC T4N0M0 or Stage III receiving surgical resection for rectal cancer. [AdjRT]							Adj RT
	90.9%	100%	92.9%	71.4%	100%	90%	100%	

Figure 1. Cancer Program Practice Profile Report. A representative report from one Commission on Cancer–accredited program with the most recent data on performance on six quality measures in breast and colon cancer from 2004 to 2010. The Case Review column provides an active link to case level data for case auditing and updating to ensure accuracy.

Figure 2. Rapid Quality Reporting System (RQRS) quality dashboard. The RQRS provides a dashboard, updated daily, on quality measures for the cancer program and provides active links to patient-level data for auditing.

registry data. The CoC harmonized these measures with similar ones developed in parallel by the American Society of Clinical Oncology and the National Comprehensive Cancer Network.¹⁸ The National Quality Forum endorsed the CoC measures in 2006 and re-endorsed them in the fall of 2012.

The CoC also established an NCDB-based system to report on performance related to these quality measures to their programs. This Cancer Program Practice Profile Report includes performance on each quality measure and the aggregate performance across other CoC accredited programs. Performance rates on these measures have been reported annually to all programs for patients treated since 2004 (Figure 1).

Prospective Quality Monitoring

A key issue with the Cancer Program Practice Profile Report program is that the annual registry data submission cycle delays

performance reporting by as much as 18 to 24 months after diagnosis. Although these reports are useful, a key tenant of quality measurement is timeliness. To speed reporting, the CoC developed a registry-based system for real-clinical-time reporting and monitoring of treatment information, the Rapid Quality Reporting System (RQRS).¹⁹ Initial diagnostic, staging, and treatment data are entered and uploaded to the CoC as soon as it is available after diagnosis. The RQRS monitors the case data and alerts the hospital registry if the National Quality Forum measure's requisite treatment is not reported in the stipulated time frame. For example, as per the measure, the treatment of a woman with hormone receptor–negative breast cancer is monitored. If the registry has not recorded that she started chemotherapy as the 4-month stipulated deadline approaches, the registry receives electronic color-coded alerts. This allows the cancer program to readily identify patients who have not re-

ceived treatment and to intervene to ensure the patient receives or is fully counseled on appropriate treatment. In addition, the RQRS provides a running tally of quality performance that is current rather than delayed 2 or more years. Figure 2 shows one hospital's RQRS quality measure dashboard.

RQRS was tested at 64 accredited programs between 2009 and 2011. It was made available to all CoC-accredited programs in September 2011. As of December 2012, more than 400 programs have adopted this system, with approximately 25% of all breast and colon cancers in the United States now treated in programs using this tracking system.

Future Use of the Registry for Quality Management

In the short-term, the CoC is adding new quality measures in breast, colon, and other cancer types for implementation in 2013. RQRS is being expanded to other disease sites and being adopted by a larger proportion of accredited programs. The informatics platforms for RQRS and other CoC reporting tools are being updated and expanded.

The CoC is also expanding its public reporting of quality data. The RQRS platform has been selected for public reporting of quality by the Prospective Payment System—exempt cancer centers, as required under the Affordable Care Act to begin in fiscal year 2014.²⁰ This will undoubtedly lead to broader public reporting of CoC quality metrics.

The CoC is also actively researching opportunities to enhance the registry system, streamline data collection, and improve quality reporting. Linking the NCDB to private payer administrative claims was recently proven feasible and was shown to provide more complete and detailed cancer treatment

data.²¹ The CoC and partners are testing the collection of patient-reported symptom and outcome data through the hospital registry. The CoC and other partners funded by the LIVES-TRONG Foundation are developing a tool using the RQRS system to autopopulate an end-of-treatment summary report linked to comprehensive clinical information that would provide a complete survivorship care plan. Future work will address a means to capture data directly from electronic health records, further streamlining data collection and quality. Finally, the CoC looks to collaborate with other organizations such as the American Society of Clinical Oncology in defining future data and systems needs in oncology.

Acknowledgment

Presented at the ASCO Quality Care Symposium, San Diego, CA, November 30-December 1, 2012.

Authors' Disclosures of Potential Conflicts of Interest

The author(s) reported no potential conflicts of interest.

Author Contributions

Conception and design: Stephen B. Edge, Andrew K. Stewart

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Stephen B. Edge, MD, Roswell Park Cancer Institute, Elm and Carlton Streets, Buffalo, NY 14263, e-mail: stephen.edge@roswellpark.org.

DOI: 10.1200/JOP.2013.000955

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