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Commentary: “Help the Doctor”—The Culture Shift to 21st Century Care Management

By Stephen B. Edge, MD

Wide variations in the quality of cancer care affect recurrence and survival. Having health insurance is that first giant “Hillary step” needed to attain the summit of quality care. However, quality varies among those with ready access to care. Improving the quality of care requires community-wide treatment data. Collecting complete data is a daunting task, and the United States has made a huge investment in population registries to evaluate cancer incidence and mortality, which may also provide the foundation for assessment of quality.

Johnson et al¹ report in *Journal of Oncology Practice* on a collaboration of state registries and the Northern New England Clinical Oncology Society (NNECOS) using data from the Vermont, New Hampshire, and Maine registries to assess breast and colon cancer care. Patients in rural settings had rates of lumpectomy and radiation for breast cancer similar to those in cities, but they were less likely to have sentinel node biopsy or receive chemotherapy for stage III colon cancer.

The Achilles heel of registry-based studies is incomplete treatment data. Cancer registries are hospital based, but cancer care is primarily not. Providers may not report to the hospital registry where the patient received surgery and may fail to independently report to a state registry. A study in California showed that the state registry only identified 72%, 56%, and 36% of incidences of administered radiation, chemotherapy, and endocrine therapy, respectively.² Johnson et al¹ state that the estimated completeness for each registry was 95%, but these figures generally refer to case identification. They attempted to get missing data from reporting facilities but do not report any audit demonstrating completeness of treatment information and only looked for treatment within 6 months of diagnosis (radiation for breast cancer is often started after 6 months). Unfortunately, the extent and variability of incomplete data are unknown, and this uncertainty limits the evaluation of outcome.

Two key issues must be addressed to truly affect patient outcomes:

Timely, complete, community-wide data for quality assessment. The current registry data collection system is cumbersome and relies heavily on provider cooperation. It is unlikely the current system will provide complete data, and existing registry data are insufficiently detailed to define care (eg, registries do not record

type or frequency of chemotherapy). Many groups are experimenting with the linkage of registry and administrative data to get complete, detailed data, mainly using insurance claims. Future data sources will include point-of-service collection through electronic health records and possibly even patient self-reporting.

Barriers to these efforts include the large number of competing payers in the United States, varied data formats, the absence of claims on uninsured persons, and legal and privacy concerns. However, there are a number of ongoing projects using aggregated public and private payer claims. A number of states have established statewide all-payer claims sets. Maine has an established program, and New Hampshire, Vermont, and Massachusetts are developing all-payer claims sets, so the NNECOS collaborative may use this in subsequent work.

Cancer data must also be collected in a timeframe that supports quality management. The nature of cancer treatment and difficulty in collecting, reporting, and aggregating data delay the availability of registry data for 1 to 3 years after treatment. Therefore, all registry studies are retrospective. Although these observations have been useful, they have no impact on the affected patients and may only affect quality tangentially. Even when these outdated quality data are presented to providers, a common response is “not in my practice.” And indeed, they are often right. Given the case volume of individual physicians, each one has only an occasional patient who “falls through the cracks.”

Collaboration. It is critical that these efforts emanate from collaborations of affected parties, including providers, payers, government, and the public. Much current effort focuses on pay for performance, potentially placing these parties at odds with one another. Unfortunately, it is too easy to blame individuals for what is really a failure of the health care system.

Real-time data collection and tracking systems with care management programs are needed to support providers and patients. Such programs improve quality. Bickell et al³ demonstrated that missed care often results from failure in care coordination. A registry-based tracking program cut missed care dramatically and virtually eliminated disparities, and physicians were eager to participate. On a large scale, these tracking programs should be based on linkages of electronic health

records, registries, and claims systems to identify patients and treatment early with care management systems, thereby assisting providers and patients in getting the best care. One early effort in this area is the Rapid Quality Reporting System of the American College of Surgeons Commission on Cancer through its National Cancer Data Base. Registrars at Commission on Cancer-accredited programs will report stage and primary treatment data to the National Cancer Data Base within 2 months of diagnosis, and the data will be monitored for intervention to assure that requisite treatment is administered in accordance with approved quality measures for breast and colon cancers.⁴

Efforts like the NNECOS project must be duplicated across the country and extended quickly to assure collection of accurate, detailed data in a timeframe supporting case management. The biggest problems are not the relatively simple technical and legal issues but rather the cultural barriers to collaboration. The

American public deserves and demands that our industry move quickly to replace our antiquated information systems and approaches to care management with 21st century solutions.

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