Using Population-Based Registries to Study Variations in Health Care

By Christopher M. Dodgion, MD, MBA, MSPH, and Caprice C. Greenberg, MD, MPH

Variations in health care exist across demographic groups, geographic regions, institutions, and even individual health care providers within a single institution. These variations are a result of a multifaceted balance between patient, physician, hospital, and health system factors. All of these factors impact health care management decisions, which ultimately determine the utilization, quality, and cost of care delivered to individual patients. The complex interactions between all of these components make it impossible to analyze one without the other.

When variations in health care were first described, single data sources, such as institutional case series, registries, and large administrative databases, had sufficient information to document that important variations existed and to measure the magnitude of those variations across defined populations.^{1,2} As investigators took the natural next step of understanding the etiology of these variations, the limitations of individual data sets became apparent. Administrative databases, for example, despite having a large amount of information about treatment received, lacked pathology results, which are critical in nearly every oncology analysis.

The Surveillance Epidemiology and End Results (SEER) registry is a population-based national cancer registry that contains detailed pathology and certain patient-level variables and allows for a more complete investigation of the factors underlying observed variations at the population level.³ However, three important data elements remain incomplete. There is no hospital variable to allow for analysis of institutional variation, and perhaps more importantly, there is limited treatment and comorbidity information required for studies of utilization and cost and adequate case-mix adjustment. These limitations were addressed by the linkage of SEER data with Medicare claims data (SEER-Medicare).⁴ As we move into the era of comparative effectiveness research, SEER-Medicare will continue to play an important role. However, limitations to this database still exist. For example, because data are only available for Medicare patients, the ability to study cancers that occur primarily in young patients (eg, testicular cancer) or in which treatment choices vary by age (eg, surgical treatment of breast cancer) is limited.

The SEER-Medicare linkage is the first and most obvious example of linking multiple data sources to answer increasingly complex questions, but many others exist and are in development. An initiative of the Cancer Surveillance and Outcomes Research Team at the University of Michigan

(Ann Arbor, MI) supplements SEER registry data from Detroit and Los Angeles with patient and physician survey data.⁵ This linkage has allowed investigation into preference-based decisions, in which there are no clear best procedures, and choices are determined by the patients' values.^{6,7} Because no two patients are the same—each has his or her own experience, cultural traditions, and values—some degree of variation is appropriate. The difficulty arises in distinguishing the wanted and warranted variations from the unwanted and unwarranted variations or disparities. This body of work has advanced our understanding of the role patient preference and patient-provider interactions play in determining treatment choice for breast cancer.^{5,6} Other studies have used linked data to highlight variations in access and disparity trends in cancer care. For example, one study linked SEER registry data to the National Longitudinal Mortality Study to show that patients with colon and breast cancers with lower socioeconomic status were more likely to present with advanced disease and have decreased survival.⁸

Despite these advances, our understanding of variations in cancer care is still quite limited. There are several possible approaches to improving our understanding of the variation and quality of cancer care in the United States. In an ideal world, we might develop a national monitoring system. Such a complex undertaking would have to be of low cost, representative of the US population, and rely on multiple data sources.^{9,10} Some have advocated for the expansion of existing registries to collect comorbidity data to properly control for case mix and to increase the clinical detail of treatment information currently collected.² However, the intensive cost and time required for manual medical record abstraction limit the universal acceptance of this approach and can lead to a substantial delay in the availability of these data for analysis. Others have advocated for the expanded linkage of population-based registries with additional administrative databases.¹¹ Finally, with the increasing adoption of electronic medical records, automated data abstraction using techniques like natural language processing is another exciting area that could facilitate more detailed and timely data collection.

Databases and registries have provided a means of describing variations in care, but they are often limited in their ability to provide a deeper look. More research is needed to understand the complex factors that underlie these variations, distinguish the wanted from the unwanted, and design and test interventions to alleviate current disparities in cancer care. Finding new ways to capitalize on the increasing availability

of electronic data will allow us as a discipline to collect and analyze point-of-care information, better understand the current state of our health care system, and ultimately ensure that all of our patients get the quality care they deserve.

Accepted for publication on September 7, 2009.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

Christopher M. Dodgion, MD, MBA, MSPH, is a research fellow in the Center of Surgery and Public Health at Brigham and Women's

Hospital and Harvard Medical School, Boston, MA. Contact him at cdodgion@partners.org.

Caprice C. Greenberg, MD, MPH, is Assistant Professor of Surgery at Harvard Medical School and a health services researcher focusing on quality of care and patient safety at the Center for Outcomes and Policy Research, Dana-Farber Cancer Institute, and the Center for Surgery and Public Health, Brigham and Women's Hospital, Boston, MA. Contact her at ccgreenberg@partners.org.

DOI: 10.1200/JOP.091041

References

1. Du XL, Key CR, Dickie L, et al: Information on chemotherapy and hormone therapy from tumor registry had moderate agreement with chart reviews. *J Clin Epidemiol* 59:53-60, 2006
2. Malin JL, Kahn KL, Adams J, et al: Validity of cancer registry data for measuring the quality of breast cancer care. *J Natl Cancer Inst* 94:835-844, 2002
3. National Cancer Institute: Surveillance, Epidemiology and End Results (SEER) program. <http://seer.cancer.gov/>
4. National Cancer Institute: SEER-Medicare linked database. <http://healthservices.cancer.gov/seermedicare/>
5. University of Michigan: CanSORT: Cancer Surveillance and Outcomes Research Team. <http://www.med.umich.edu/cansort>
6. Hawley ST, Hofer TP, Janz NK, et al: Correlates of between-surgeon variation in breast cancer treatments. *Med Care* 44:609-616, 2006
7. Collins ED, Moore CP, Clay KF, et al: Can women with early-stage breast cancer make an informed decision for mastectomy? *J Clin Oncol* 27:519-525, 2009
8. Clegg LX, Reichman ME, Miller BA, et al: Impact of socioeconomic status on cancer incidence and stage at diagnosis: Selected findings from the surveillance, epidemiology, and end results: National Longitudinal Mortality Study. *Cancer Causes Control* 20:417-435, 2009
9. Desch CE, McNiff KK, Schneider EC, et al: American Society of Clinical Oncology/National Comprehensive Cancer Network Quality Measures. *J Clin Oncol* 26:3631-3637, 2008
10. Schneider EC, Malin JL, Kahn KL, et al: Developing a system to assess the quality of cancer care: ASCO's national initiative on cancer care quality. *J Clin Oncol* 22:2985-2991, 2004
11. Coory M, Thompson B, Baade P, et al: Utility of routine data sources for feedback on the quality of cancer care: An assessment based on clinical practice guidelines. *BMC Health Serv Res* 9:84, 2009

ARE YOU READY FOR THE NEXT STEP IN YOUR CAREER? ACHIEVING CAREER SUCCESS IN ONCOLOGY: A PRACTICAL GUIDE CAN HELP.

Achieving Career Success in Oncology offers expert advice on managing your career in each of the major paths: academia, community practice, government and the pharmaceutical industry. Order your copy at www.asco.org/careerguide.

American Society of Clinical Oncology