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ORIGINAL ARTICLE – HEALTHCARE POLICY AND OUTCOMES

Value-Based Breast Cancer Care: A Multidisciplinary Approach for Defining Patient-Centered Outcomes

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ABSTRACT

Purpose. Value in healthcare—i.e., patient-centered outcomes achieved per healthcare dollar spent—can define quality and unify performance improvement goals with health outcomes of importance to patients across the entire cycle of care. We describe the process through which value-based measures for breast cancer patients and dynamic capture of these metrics via our new electronic health record (EHR) were developed at our institution.

Methods. Contemporary breast cancer literature on treatment options, expected outcomes, and potential complications was extensively reviewed. Patient perspective was obtained via focus groups. Multidisciplinary physician teams met to inform a 3-phase process of (1) concept development, (2) measure specification, and (3) implementation via EHR integration.

Results. Outcomes were divided into 3 tiers that reflect the entire cycle of care: (1) health status achieved, (2) process of recovery, and (3) sustainability of health. Within these tiers, 22 patient-centered outcomes were defined with inclusion/exclusion criteria and specifications for reporting. Patient data sources will include the Epic Systems EHR and validated patient-reported outcome questionnaires administered via our institution's patient portal.

Conclusions. As healthcare costs continue to rise in the United States and around the world, a value-based approach with explicit, transparently reported patient outcomes will not only create opportunities for performance improvement but will also enable benchmarking across providers, healthcare systems, and even countries. Similar value-based breast cancer care frameworks are also being pursued internationally.

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The cost of providing care to cancer patients continues to increase both in the United States and around the world, and one of the major contributors to this increase in expenditure is the care of patients with breast cancer, the most common malignancy in women.[1] Advances in screening and changes in women's lifestyles and reproductive patterns caused the incidence of female breast cancer to rise significantly in the 1980s.[2] However, advances in treatment have also led to improved survival and consequently to the creation of a large and growing population of breast cancer survivors, a well-informed, energized base of women who are helping redefine the landscape of the disease.[3] These patients—most of whom are ultimately cured, and some of whom live for many years with metastatic breast cancer as a chronic disease—are actively participating in efforts to place patients at the center of the care they receive by helping give voice to clinical outcomes and experiences that are of greatest importance to patients.[3–5] At the same time, it has become clear that patient-centered care should also be a goal of healthcare providers and payers with respect to both cost-effectiveness and quality improvement, a concept that represents the central tenet of value-based care.

A value-based approach to healthcare represents a shift away from the primarily process-based measures that have historically set the throughput-oriented targets of providers and payers at odds with the more time-intensive and qualitative aims embraced by patients. This is not to say that conventional process measures for assessing and optimizing the quality of breast cancer care are not important. But "value," as first proposed by Porter and Teisberg at Harvard Business School, is a uniquely global metric for defining healthcare quality because it refers to the end result of all combined practices.[6] Defined as patient health outcomes achieved per healthcare dollars spent, value unifies the performance-improvement goals of providers with indicators of high-quality care that are important to and reported by patients. As healthcare moves towards a value-based framework for gauging success and improving quality, one of the principal challenges of this approach will be accurately and systematically capturing the outcomes that will form the numerator of the value equation. The current moment in time represents an important opportunity: as institutions work to comply with a federal requirement for universal adoption of electronic health records (EHRs), the collection of patient-reported outcomes (PROs) must be integrated into institutions' EHR platforms.[7]

In the spring of 2016, the University of Texas MD Anderson Cancer Center will officially transition its current EHR platform to Epic Systems, and dedicated teams of MD Anderson staff have been engaged in an expedited effort to optimize and standardize PRO data collection in the soon-to-be implemented system. Given its prevalence and projected contribution to the continuing surge in cancer care expenditures, breast cancer is one of the first conditions for which the collection of patient-centered quality metrics via the new EHR will be piloted. Here, we describe the process through which value-based measures for breast cancer patients and dynamic capture of these metrics via our new EHR were developed at our institution.

METHODS

Faculty Working Group

MD Anderson's Institute for Cancer Care Innovation (ICCI) was founded in 2008 to address the evolving landscape of healthcare cost and delivery, and its initiatives are rooted in value-based tenets. In June 2013, when MD Anderson announced plans to replace the institution's longstanding, internally developed ClinicStation EHR system with the Epic Systems EHR platform, ICCI was engaged as an important player in this transition. ICCI specifically sought faculty members with an established interest in outcomes research and quality improvement to establish a breast cancer working group, consisting of 10 physicians who would develop outcome measures for integration into the new EHR.

Patient Focus Groups

Given the importance of patient perspective to the identification of high-value outcomes, MD Anderson sought to incorporate patients' beliefs and values in developing the metrics that would be included in the Epic Systems EHR. Gelb Consulting Group (Houston, TX, USA), a marketing research and consulting firm, had been retained by MD Anderson to assess the needs, perceptions, and preferences of cancer patients regarding their use of outcomes information by facilitating patient focus groups. A recruitment goal of 12 participants was determined, with a minimum number of 8 participants deemed to be sufficient to achieve response saturation. Recruitment deliberately targeted a patient cohort that was diverse with regards to age, education level, ethnicity, and income. Informed consent was obtained from all patients before focus group participation.

Focus group discussions were audio-recorded in real time and transcribed. Topics of discussion included (1) understanding the basis for patients' deciding to select MD Anderson, (2) assessing patients' understanding of what "outcomes" are, (3) having patients describe the relative importance of different types of outcomes, (4) discovering how patients use outcomes information, and (5) determining patients' preferred sources of outcomes information. Summaries of participants' responses were provided to the breast cancer working group with the intention that these synopses would guide the group's efforts to develop outcome metrics for incorporation into the new EHR.

Outcome Metric Development

Members of the working group conducted an extensive review of the world literature examining current breast cancer diagnosis and treatment guidelines as well as treatment risks, benefits, and complications; published sources of previously described, oncology-specific quality metrics; validated PRO questionnaires; and important cohort studies, meta-analyses, and randomized clinical trials that have shaped breast surgical, medical, and radiation oncology (Online Appendix). The working group convened approximately 12 times over the course of 1 year as part of a 3-phase process of (1) concept development, during which a comprehensive list of outcomes was generated and agreed upon by members; (2) measure specification, as part of which definitions, data collection time points, inclusion and exclusion criteria, data stratification criteria, and existing and future data sources for each outcome metric were determined; and (3) implementation of metric collection via EHR integration, which involved working with Epic Systems consultants and an internal EHR-transition working group.

RESULTS

Focus Group Conclusions

The breast cancer patient focus group included 8 women with a mean age of 53.6 years. Three participants were non-Hispanic white, 3 were non-Hispanic African American, and 2 were Hispanic. All but one considered herself the sole maker of her healthcare decisions, and 6 had at least some college education; only 2 participants had a household income of ≥$75,000 per year. With regards to their understanding of clinical outcomes and how they might be relevant to their own decision making and overall satisfaction, focus group participants had difficulty relating to the word "outcomes," instead preferring language such as "what my life will be like" or "medical results." Furthermore, when asked what outcomes were important to them, patients reported a number of nonoutcome entities (e.g., "experts," "CT scan"). However, participants did also report the following as outcomes they thought were significant: prognosis, survival rate, recurrence, adverse effects, and percentage cured.

Outcome Metrics

Outcomes were divided into 3 tiers, as previously defined by Porter, that reflect the entire cycle of care (Table 1): health status achieved (Online Appendix Table 1), process of recovery (Online Appendix Table 2), and sustainability of health (Online Appendix Table 3).[8] Within these tiers, 22 patient-centered outcomes were defined for breast cancer. Survival and recurrence outcomes (Online Appendix Table 1) will be limited to patients who receive all treatments (i.e., surgery, radiotherapy, chemotherapy, and endocrine therapy) at MD Anderson. Existing data sources include MD Anderson's historical EHR system (ClinicStation), the MD Anderson tumor registry, and Enterprise Information Warehouse (i.e., MD Anderson's data warehouse, which includes institu-

TABLE 1 Value-based outcome metrics for breast cancer care

Tier 1: Health status achieved	Survival and disease control	Overall survival (5-year, 10-year) Disease-free survival (5-year, 10-year) Recurrence (yes/no, 5-year, 10-year)
	Degree of recovery and functional status	Return to normal activities of daily living Return to work status
Tier 2: Process of recovery	Treatment time and access	Access to care (≤10 days) Treatment delay (>30 days)
	Disutility of care or treatment process	Reoperation[a] Treatment-related emergency department visits[b] Readmission[b] Infection requiring antibiotics[b]
Tier 3: Sustainability of health	Long-term consequences of therapy	Appearance satisfaction[c] Patient-reported lymphedema[c] Fatigue[c] Physical intimacy[c] Pain[c] Physical well-being[c] Social well-being[c] Fertility preservation (premenopausal patients only) Cognitive dysfunction[c] Neuropathy[c] Osteoporosis[c]

Expanded tables of metrics are available in the Online Appendix

[a] Within 30 days of surgery

[b] Within 90 days of surgery

[c] Baseline and at 1, 3, and 5 years after surgery

tional billing records). With implementation of the new EHR (Epic Systems) and the ongoing transition to an Oracle-based Federated Institutional Reporting Environment, more robust electronic systems will serve as the future data sources for these metrics. Additionally, a validated PRO questionnaire, FACT-B+4, will be administered via our institution's online patient portal (myMDAnderson) before treatment, quarterly for the first 2 years after presentation to MD Anderson, and then yearly.[9] The ability to access myMDAnderson outside the clinical setting minimizes the bias previously demonstrated to confound patients' responses on the quality of care they receive.[10]

DISCUSSION

In the United States and throughout the world, the cost of healthcare is increasing, and, for delivery of care to cancer patients, this steady rise in costs is particularly precipitous. Although the cost of cancer care constitutes a relatively small proportion of overall healthcare dollars spent in the United States, it contributes disproportionately to the rate of increase in domestic healthcare expenditure.[11] It is projected that between 2010 and 2020, the cost of cancer care in the United States will increase by 27 %, from $125 billion to $158 billion.[1,11] As implementation of the Affordable Care Act of 2010 (ACA) has alleviated many access and coverage barriers to cancer care, an important opportunity exists to dovetail this improved access to healthcare with improvements in the quality and cost of the care that is delivered. Recognizing this opportunity for reform, the U.S. Department of Health and Human Services has identified oncology care as one of the first specialty fields in which novel payment and care coordination models will be developed and implemented in the wake of ACA enactment.[7] Furthermore, leaders of the Centers for Medicare and Medicaid Services (CMS) have designated 2018 as the year by which they want at least half of their payments to come through accountable care organizations, bundled care payments, and other value-oriented payment models.[7] Because this process is still in its very earliest stages, it is of critical importance that cancer centers play an active role in the creation and deployment of these models, shaping them with the benefit of real-world experience so that they can truly reflect the vested interests of patients, providers, and other non-governmental stakeholders.

As discussed, one of the largest contributors to the projected increase in cancer care expenditure is the ongoing care of breast cancer patients and survivors, calculated to represent nearly one third of the expected $33 billion increase over 10 years.[1] Breast cancer is already the most commonly diagnosed cancer in women, representing 29 % of all newly diagnosed cancers in U.S. women in 2014.[2] However, as the cadre of breast cancer survivors grows ever larger, it is necessary to incorporate their experiences into our collective understanding of what health and wellness look like after cancer diagnosis, treatment, and cure. Furthermore, as Americans increasingly find themselves contributing to the payment of their own healthcare costs, patients will also need to play a part in the drive toward cost containment and quality improvement in oncology care, and this patient-centered approach forms the core of value-based care.[11]

As described by Porter and Teisberg, 7 principles constitute the concept of value-based competition in healthcare, as follows.[6]

1. Establishing value for patients—as opposed to maximal volume or minimal cost—as the principal goal of healthcare delivery.
2. Recognizing that improvement in quality (i.e., health outcomes) ultimately facilitates both containment of costs and improvements in value.
3. Organizing the delivery of healthcare around medical conditions, rather than medical providers, and examining the quality of care delivery over the entire cycle of care, from diagnosis to cure (or chronicity).
4. Acknowledging that greater provider and institutional experience with medical conditions facilitates improvement in value, as demonstrated by multiple studies showing that higher procedure volume often correlates with superior outcomes.[12–14]
5. Fostering regionalization of services, as opposed to duplicating services in geographically clustered facilities.
6. Measuring and publicly reporting outcomes and costs for all medical conditions and all providers in order to promote improvement and drive competition.
7. Aligning value with reimbursement by centering payment on medical conditions and cycles of care rather than discrete services (e.g., bundling payments).

CMS already displays cost, charge, and quality data on its Medicare Web site for public consumption, and both the ACA-established Patient-Centered Outcomes Research Institute and the Agency for Healthcare Research and Quality are committed to generating patient-centered quality information and disseminating it, in part through EHRs.[7] Launched in 2011, CMS's Meaningful Use incentive program was developed not only to encourage physician adoption of EHRs but also to inspire innovative EHR utilization to lower costs and improve the quality of care delivered to patients in ways that would be meaningful to them such as e-prescribing and direct e-mail communication with providers. In January 2016, CMS administrator

Andy Slavitt announced the end of the Meaningful Use program and plans to develop a new and improved system that will be less bureaucratic and more clinically relevant, that will feature greater patient engagement, and in which providers will be rewarded for positive outcomes achieved with their patients.[15] The integration of patient-centered outcomes—including outcomes directly reported by patients themselves—into our new EHR anticipates this planned modification and will facilitate the transparent reporting of outcomes as well as interfacility benchmarking, both of which are becoming important features of the healthcare environment. Furthermore, the Care Everywhere network feature in Epic Systems—which facilitates secure, interprovider access to the electronic medical records of shared patients—may, in the future, facilitate the collection, compilation, and analysis of patient-centered outcomes across the care cycle even if this care occurs at multiple different geographic locations for a given patient.

Another major advantage of a value-based framework over a process-based approach is that it unifies providers across specialties. As with most malignancies, breast cancer is treated with multiple modalities, and providers sometimes have competing interests in meeting required, treatment-related levels of activity that may even be linked to salary. When the goal is not related to the number of treatments given by a specific specialty but rather to how best to help patients avoid recurrence while also minimizing the risks of treatment (e.g., lymphedema), the overall cost of treatments will fall, and value will increase. Thus, the involvement of physicians from different specialties is critical to the development of a value-based framework for assessing the multimodal management of malignancies.

Similar cost containment and performance improvement challenges are being experienced throughout the world, and with regards to breast cancer, an approach similar to MD Anderson's is also being pursued at an international level. Porter, in his capacity as director of the Institute for Strategy and Competitiveness at Harvard Business School, partnered with leaders from the Boston Consulting Group and the Karolinska Institutet in Sweden to found the International Consortium for Health Outcomes Measurement (ICHOM) in 2012.[16] ICHOM is a nonprofit organization founded with the intent to develop standardized, globally applicable metrics for assessing the quality of healthcare delivery as it relates to various disease processes. ICHOM working groups have been established for a number of conditions, and a diverse array of clinicians, patients, economists, statisticians, and policy makers make up these groups. Disease-specific metrics for value-based care delivery—known as Standard Sets—have already been completed for 12 conditions (including prostate and lung cancer), and ICHOM aims to have completed Standard Sets for 50 conditions by 2017. The ICHOM Standard Set for breast cancer is currently in progress. Diversity of perspective and experience among healthcare organizations from around the world will contribute not only to the development of robust, culturally sensitive metrics but will also give providers a global common language that will allow innovations and improvements to be transferred and benchmarked on both a domestic and international scale. Through incorporation of validated, patient-centered outcomes such as ICHOM's Standard Sets and in collaboration with their own EHR developers, providers in this country and around the world can begin to develop value-centered metrics for patient care at their institutions, but this development will require the time and commitment of physician leaders as well as broad-based institutional support.

As healthcare costs continue to rise around the world, an EHR-integrated, value-based framework for healthcare delivery with explicit, transparently reported patient outcomes will not only create opportunities for performance improvement across the breast cancer care continuum but will also enable internal and external benchmarking across providers, systems, and even countries. A value-based framework for breast cancer care is new for MD Anderson and represents an important opportunity: we hope that its integration into our programs will lead to improved patient outcomes and that our experience might serve as a model for innovation in an evolving climate of healthcare delivery.

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