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Review Article

Society of Gynecologic Oncology Clinical Outcomes Registry: From small beginnings come great things

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HIGHLIGHTS

- The COR exemplifies a subspecialty database for gynecologic oncologic malignancies; cervical, ovarian and endometrial cancers.
- SGO members at COR sites have benefited from using registry for institutional quality review and MOC requirements.
- Data from the registry has lasting implications for outcomes research, SGO projects and national quality reporting.

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ABSTRACT

Objective. Clinical registries within medical societies have demonstrated the capacity to promote quality improvement. Opportunities for well-designed data repositories could yield reliable national standards for informing reimbursement, determining adherence to care guidelines, maintaining board certification, and developing bundled payment models. Looking to the future, we set out to develop a gynecologic cancer registry serving the members of the Society of Gynecologic Oncology (SGO).

Methods. The SGO Clinical Outcomes Registry (COR) initiated a web-based data entry platform as a foray into developing a functional registry, compiling data elements specific to gynecologic oncology. Endometrial and ovarian cancer patients began enrollment in early 2014. Within one year, 19 sites were participating with the addition of cervical cancer patients in January 2015.

Results. To date, >6500 patients are currently entered from 29 sites, and the COR is being queried to address topics of quality improvement, disparities, and cancer outcomes.

Conclusions. The SGO COR has proven the feasibility of developing a functional gynecologic cancer registry, with high uptake, rapid accrual, and ability to investigate topics of quality and outcome using the COR.

Contents

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1. Introduction

The origin of clinical registries largely arose from a desire to gather data on rare diseases in an attempt to identify causative factors or worrisome trends. Within gynecologic oncology, one of the earliest and best-known registries focused on patients with clear cell adenocarcinoma of the vagina and/or cervix. Established in 1971, this allowed for centralized data collection and varying information on the epidemiology, clustering and pathology of these tumors. Development of this registry proved instrumental in identifying diethylstilbestrol (DES) exposure as a causative factor, thereafter leading to changes in clinical behavior [1]. Other early registries, including the New England Trophoblastic Disease Center (1965) and the Familial Ovarian Cancer Registry (1981; later renamed after Gilda Radner) were similarly valuable in collating clinical data for relatively rare diseases [2,3]. The cumulative result was an improved ability to alert the discipline to disease-specific events, while identifying the most effective treatments and even providing sufficient background to design clinical trials.

Beyond these pioneering attempts at diagnoses of limited scope, the organized collection of cancer outcomes data was more problematic. In 1973, the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) began collecting data in five states and two metropolitan areas. Over subsequent years, the SEER Program expanded from modest origins to now collecting and publishing cancer incidence and survival data from population-based cancer registries covering approximately 28% of the US population [4]. Yet even by the 1990s, ten states had no cancer registry, and most states with registries lacked the resources and legislative support they needed to gather complete data. To address the basic public health need to monitor the overall burden of cancer, Congress passed the Cancer Registries Amendment Act in 1992, establishing the National Program of Cancer Registries (NPCR). Administered by the Centers for Disease Control and Prevention (CDC), the NPCR supports central cancer registries in 45 states that represent 96% of the US population [5]. Together, the NPCR and the SEER Program collect data for the entire US population to identify additional needs for cancer prevention and control efforts at the national, state and local levels.

Another registry, the National Cancer Database (NCDB), is a joint program of the Commission on Cancer (CoC) of the American College of Surgeons (ACS) and the American Cancer Society, serving as a nationwide oncology outcomes database. Data elements are collected and submitted to the NCDB from CoC-accredited cancer registries using nationally standardized data item and coding definitions. Begun in 1989, the NCDB now is a massive database with over 30 million historical records, covering 1500 sites, and approximately 70% of all cancer diagnosis in the United States and Puerto Rico [6]. The ACS CoC-accredited sites use the NCDB data to ensure their own quality and identify areas for improvement. SGO has partnered with the CoC to develop gynecologic oncology quality measures that are now incorporated into the CoC quality measures. Together the SEER Program and NCDB collect invaluable cancer data from the majority of the US population. Yet, even with the addition of a few carefully selected quality measures, the available data is not specific enough to meet the future needs for gynecologic oncology patients and the SGO's efforts to improve care. Importantly, the lack of continuous prospective data collection hinders efforts to improve patient outcomes.

Other subspecialty-specific clinical outcomes registries have proven very successful resulting in important improvements in quality and patient outcomes (i.e. compliance with subspecialty referral for specific surgical procedures). The Society of Thoracic Surgeons (STS) National Database was established in 1989 as an initiative for quality improvement and patient safety. By 1993, 530 hospitals were participating, representing 40% of the cardiothoracic surgical community and including approximately 216,000 procedures [7]. The Database has since grown exponentially, in both participation and stature, to become the gold standard for specialty clinical registries. One underlying principle of the STS is the assertion that physicians are in the best position to measure clinical performance accurately and objectively. The database has helped members of STS improve their own quality of care, make accurate comparisons on regional and national benchmarks, and use the data to predict patient outcomes. Moreover, this database has given STS enormous credibility in Congress, promoting its own members to help change policy.

Another successful national registry in the American College of Surgeons National Surgical Quality Improvement Program (ACS NSQIP), data is obtained using trained nurse abstractors rather than through administrative means. Results are blinded, audited, and risk- and case-mix-adjusted, allowing national benchmarking. As of 2017, a PubMed search of "NSQIP" yields in excess of 1500 publications with approximately 350 new publications annually. ACS NSQIP has also had an important impact on patient outcomes and is commonly used for surgical quality improvement. Over a follow-up period of eight years, approximately 70% of hospitals participating in ACS NSQIP reduced surgical complications and two-thirds improved mortality, with cost savings of millions of dollars [8,9]. Nearly 700 hospitals have contributed to the over 4 million cases in the participant user files since 2006.

An example of a registry, specific to gynecology, is the New Mexico Pap Registry. This was started in 2006 and is a partnership between the New Mexico Department of Health and the University of New Mexico. All pap and HPV tests are required to be reported to this registry under a state code. This aspect is key to provide data state wide and vital for its success. Multiple publications have resulted from this registry. It is a unique population based cervical screening registry that has been able to be linked to the HPV vaccine and helped shape public health [10].

The Health Information Technology for Economics and Clinical Health (HITECH) Act and Affordable Care Act (ACA) emphasized the importance of specialty registries and provided additional motivation to develop our own COR. Briefly, HITECH was enacted in 2009, which resourced money to promote and expand the adoption of health information technology, with the ACA continuing to promote electronic health records and technology [11]. However, with the current political climate and possible repeal of the Affordable Care Act, it is difficult to predict the future. Nevertheless, there is increasing emphasis across the health care industry to use registries to benefit clinicians, patients, and purchasers of health care services. This is no registry specific to our unique field of gynecologic oncology. Some registries do capture gynecologic oncology data, for example SEER, but is limited by data elements that are vital to the treatment of a patient with a gynecologic cancer, (i.e. residual disease status). The most important challenges involve creating a system in which clinicians are rewarded for their participation, and making data entry easy and inexpensive, while providing consistent clinical value to clinicians, policy-makers, purchasers, and payers. With an increasing national focus on measuring quality, the opportunity to leverage clinical registries to improve outcomes has never been higher.

2. SGO Clinical Outcomes Registry

With the impetus to construct our own registry, one of the critically important initial tasks was to create a consensus about which data elements to include. Working groups within our pre-existing SGO committee structure were formed by disease site for endometrial and ovary, then later cervix. Once vetted and confirmed, the selected data elements best representing the unique needs in gynecologic oncology were adopted for inclusion. In 2016, the COR working group convened to revise the initial data element set in response to feedback provided by participant experience with the original database.

The SGO COR, as a functioning entity, began to crystallize during the 2013 SGO Annual Meeting on Women's Cancer® in Los Angeles through the Quality and Outcomes Committee. Once the data elements had been established by the working groups, the software vendor was identified

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