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Prostate Cancer Registries: Current Status and Future Directions

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Abstract

Context: Disease-specific registries that enroll a considerable number of patients play a major role in prostate cancer (PCa) research.

Objective: To evaluate available registries, describe their strengths and limitations, and discuss the potential future role of PCa registries in outcomes research.

Evidence acquisition: We performed a literature review of the Medline, Embase, and Web of Science databases. The search strategy included the terms *prostate cancer, outcomes, statistical approaches, population-based cohorts, registries of outcomes, and epidemiological studies*, alone or in combination. We limited our search to studies published between January 2005 and January 2015.

Evidence synthesis: Several population-based and prospective disease-specific registries are currently available for prostate cancer. Studies performed using these data sources provide important information on incidence and mortality, disease characteristics at presentation, risk factors, trends in utilization of health care services, disparities in access to treatment, quality of care, long-term oncologic and health-related quality of life outcomes, and costs associated with management of the disease. Although data from these registries have some limitations, statistical methods are available that can address certain biases and increase the internal and external validity of such analyses. In the future, improvements in data quality, collection of tissue samples, and the availability of data feedback to health care providers will increase the relevance of studies built on population-based and disease-specific registries.

Conclusions: The strengths and limitations of PCa registries should be carefully considered when planning studies using these databases. Although randomized controlled trials still provide the highest level of evidence, large registries play an important and growing role in advancing PCa research and care.

Patient summary: Several population-based and prospective disease-specific registries for prostate cancer are currently available. Analyses of data from these registries yield information that is clinically relevant for the management of patients with prostate cancer.

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1. Introduction

Although several management options with improving long-term outcomes are currently available for patients with prostate cancer (PCa) [1], further research is still needed to improve the clinical management of this disease.

Historically, important research topics were investigated by studies that evaluated cohorts from single referral institutions. Numerous limitations often preclude generalization of results obtained in this setting. Similarly, the inclusion of highly selected patient groups, as well as costs and feasibility issues, can limit the validity of the small number of randomized controlled trials (RCTs) in the field of PCa [2]. The increasing availability of cancer registries, defined as organized systems that collect uniform data for a population defined by a particular disease, together with the improvements in data processing capabilities, has transformed PCa outcomes research during the last two decades [3–5].

The aim of this review is to evaluate currently available population-based and prospective disease-specific registries, to describe their strengths and limitations, to illustrate the types of studies that can be performed using these data, and to discuss the potential role of PCa registries in outcomes research in the future.

2. Evidence acquisition

A literature review was performed in January 2015 using the Medline, Embase, and Web of Science databases. The search strategy included the terms *prostate cancer*, *outcomes*, *statistical approaches*, *population-based cohorts*, *registries of outcomes*, and *epidemiological studies*, alone or in combination. We limited our search to population-based studies and investigations performed using prospective PCa registries published from January 2005 to January 2015. References cited in selected articles and in review articles retrieved in our search were also used to identify manuscripts that were not included in the initial search. The articles that provided the highest level of evidence were then evaluated and selected with the consensus of all authors of this manuscript. A total of 103 articles were reviewed.

3. Evidence synthesis

3.1. A role for PCa registries

According to current guidelines, the highest level of evidence and strongest grade of recommendation are provided by results of RCTs or meta-analyses of such studies [1]. Nonetheless, several issues often preclude generalization of results obtained in RCTs. First, these studies are in part limited by poor accrual; in fact, approximately 20% of adult cancer trials are never completed [6]. Second, patients participating in RCTs are often highly selected and might substantially differ from those seen in routine practice [3,7–11]. Third, RCTs are expensive. As a consequence, industry-funded studies are

common in this setting [12]. However, sponsored trials are more likely to be published if positive in comparison to independent studies, which can be another source of bias [13,14]. Finally, RCTs, particularly in early PCa, take a long time to complete. Therefore, results from these studies might be obsolete by the time sufficient follow-up is achieved.

Observational studies represent an alternative to RCTs. Such studies are usually characterized by lower costs, higher patient numbers, more rapid accrual, and consequently a shorter time for identification and dissemination of results [15,16]. However, despite statistical controls, selection bias may affect results from single- and multi-institutional series [16,17]. In addition, most observational studies generally include men treated at high-volume tertiary referral centers. Since surgeon, radiotherapist, and oncology expertise, as well as hospital case volumes, affect treatment-related outcomes [18–21], results obtained in this setting might not be applicable to the general population. Unlike the majority of cancer data sets from large, highly specialized, single-center academic or tertiary referral institutions in the USA and Europe, registries reflect outcomes in men with PCa treated in real-world community settings. Moreover, because the data are primarily community- or population-based, they represent a meaningful standard of comparison for benchmarking at the individual, local, regional, or national level.

The significant practical limitations of RCTs and the bias and applicability concerns that may plague single-center cohort studies highlight the need for other sources of data to study PCa screening, diagnosis, treatment, and outcomes. PCa registries provide such an alternative. The democratization of patient management to a larger or general population creates a more generalizable pool for analysis and subsequent conclusions [3,4,15].

3.2. Types of PCa registries

PCa registries include both population-based and/or community cohorts and prospective patient registries. The term *population-based* refers to the systematic and ongoing collection of data on all patients (or a random sample of the overall population) with a certain disease resident in a given geographic area within a given time period [22–24]. These registries collect a standardized set of variables for every case of the disease in question occurring within a well-defined population. Developed in the first half of the 20th century to provide an understanding of the scale and profile of cancer within communities, and to elucidate causes of variations between and within populations over time, population-based cancer registries in higher-income settings have evolved and frequently measure and assess patterns and quality of care, as well as longitudinal patient outcomes [4,17,25–27].

Clinical registries dedicated to specific cancers exist in the USA, Asia, Australia, and several European countries. Clinical registries collect additional detailed information on diagnostic procedures, pathology examinations, treatment, and follow-up. Importantly, the coding system and

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