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Review Article

A Multisource Approach to Improving Epidemiologic Estimates: Application to Global B-Cell Malignancies

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The compilation of comprehensive, worldwide epidemiologic data can inform hypotheses on cancer etiology and guide future drug development. These statistics are reported by a multitude of sources using varying methods; thus, compiling a complete database of these statistics is a challenge. To this end, this paper examined the usefulness of a novel, multisource approach—extracting data from the peer-reviewed literature, online reports, and query systems from cancer registries and health agencies and directly contacting cancer registry personnel—for building a comprehensive, multinational epidemiologic cancer database. The major B-cell malignancies were chosen as the cancer subtype to test this approach largely because their epidemiology has not been well characterized in the peer-reviewed literature. We found that a multisource approach yields a more comprehensive epidemiologic database than what would have been possible with the use of literature searches alone. In addition, our paper revealed that cancer registries vary considerably in their methodology, comprehensiveness, and ability to gather information on specific B-cell malignancy subtypes. Collectively, this paper demonstrates the feasibility and value of a multisource approach to gathering epidemiologic data.

1. Introduction

Descriptive epidemiologic statistics assist public health planning and provide valuable information about the burden of illness to policy makers, funding agencies, resource planners, healthcare insurers, and manufacturers. Information on malignancies that is compatible with their clinical classifications is of particular value to clinicians and public health professionals and increasing efforts are being made to collect data at this detailed level (e.g., the HAEMACARE project [1]). It is challenging, however, to assemble a database of descriptive epidemiologic statistics from the peer-reviewed literature alone. Cancer registries are used worldwide to collect and analyze demographic, diagnostic, and survival data. Some registries are fraught with poor quality and infrastructure; however, there is no standardized system for the collection and reporting of descriptive statistics worldwide [2, 3]. Comprehensive reviews of descriptive epidemiologic statistics, such as this one, are warranted to better understand the totality of the currently available data and to optimize the utility of such data in the future.

This paper uses a particular cancer subtype—B-cell malignancies—to evaluate a novel approach to assembling a database of worldwide, national-level, descriptive epidemiologic cancer statistics. This approach incorporates information from various sources, including the peer-reviewed literature, online reports, and query systems from cancer registries and health agencies, and direct contact with cancer registries, to provide a current, comprehensive database for a representative group of countries worldwide. The major B-cell malignancies were chosen as the cancer subtype to test this approach largely because their epidemiology has not been well characterized. Further, some B-cell malignancy subtypes require detailed diagnostic evaluation, and this paper allowed us to broadly assess the extent to which detailed diagnoses are currently being reported to cancer