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Measuring the effect of improvement in methodological techniques on data collection in the Gharbiah population-based cancer registry in Egypt: Implications for other Low- and Middle-Income Countries

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ABSTRACT

The purpose of this study was to describe and quantify procedures and methods that maximized the efficiency of the Gharbiah Cancer Registry (GPCR), the only population-based cancer registry in Egypt. The procedures and measures included a locally-developed software program to translate names from Arabic to English, a new national ID number for demographic and occupational information, and linkage of cancer cases to new electronic mortality records of the Ministry of Health.

Data was compiled from the 34,058 cases from the registry for the years 1999–2007. Cases and registry variables about demographic and clinical information were reviewed by year to assess trends associated with each new method or procedure during the study period.

The introduction of the name translation software in conjunction with other demographic variables increased the identification of detected duplicates from 23.4% to 78.1%. Use of the national ID increased the proportion of cases with occupation information from 27% to 89%. Records with complete mortality information increased from 18% to 43%. Proportion of cases that came from death certificate only, decreased from 9.8% to 4.7%.

Overall, the study revealed that introducing and utilizing local and culture-specific methodological changes, software, and electronic non-cancer databases had a significant impact on data quality and completeness. This study may have translational implications for improving the quality of cancer registries in LMICs considering the emerging advances in electronic databases and utilization of health software and computerization of data.

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1. Introduction

Cancer registration plays a key role in defining the magnitude of cancer in populations and planning and evaluating cancer prevention and control interventions. Population-based cancer registries are essential for calculating cancer incidence and trends and setting the stage for the generalization of epidemiologic and clinical studies to populations [1]. Population-based cancer registries are of increasing importance in Low- and Middle-Income Countries (LMICs) as they experience epidemiologic and nutritional transitions [2]. In Africa, the total population is expected to increase by 60% by 2030, with the population over 65 expected to increase by 90% [3]. These changes will lead to a significant increase in cancer incidence and mortality especially in these populations of limited medical resources, poor recording of clinical information, and very limited cancer registration.

The International Agency for Research on Cancer (IARC) has included only 8 cancer registries from Africa in its last version of Cancer Incidence in Five Continents' (CI-5) monographs [4]. In order to be included in CI-5 a registry must meet certain high data quality standards. The Gharbiah Population-based cancer Registry (GPCR) in Egypt has been one of these few registries in the last 2 versions of CI5 [4,5]. The GPCR was established in 1999 in collaboration with the Middle East Cancer Consortium and the National Cancer Institute of the United States in the Gharbiah province in the center of the Nile Delta region [6,7]. Through an

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active registration process, the registry collects information about incident cancer cases that are diagnosed annually among the approximately 4.5 million residents of the province [7].

At the inception of the registry, the standard international registration software and manuals developed and used by IARC and SEER were utilized in Gharbiah to collect and record data [8]. However, through the registration process it was realized that additional locally-tailored procedures and methods were needed for improving the completeness of data and data quality of the registry. Therefore, we conducted this study to describe these procedures and methods and to quantify their impact on the data collection process. The new procedures and methods included: (a) developing and using a software to translate Arabic names to English in order to better detect duplicates in registration; (b) including and using a newly-developed Egyptian national identification number (ID) and the corresponding demographic information; and (c) utilizing a newly electronic mortality record database developed by the Egyptian Ministry of Health.

2. Materials and methods

2.1. The Gharbiah population-based cancer registry (GPCR)

The GPCR was founded in 1998 by the National Cancer Institute (NCI) of the United States as part of the Middle East Cancer Consortium (MECC) [6]. The registry is located in Tanta, the capital city of the Gharbiah province of Egypt. The population of Gharbiah is about 4.5 million and it represents about 5.4% of the total population of Egypt [9]. The registry collects the majority of information for over 75% of the cancer cases from 3 main sources: the Tanta Cancer Center, The Gharbiah Cancer Society hospital, and The Tanta University Medical School. Other sources for data collection included public and private pathology laboratories, hospitals and clinics; and the Ministry of Health mortality records.

As mentioned above, through the registration process it was realized that additional locally-tailored procedures and methods were needed for improving the completeness of data and data quality of the registry. The new procedures and methods included: (a) developing and using a software to translate Arabic names to English in order to better detect duplicates in registration; (b) including and using a newly-developed Egyptian national identification number (ID) and the demographic information; and (c) utilizing a newly-developed electronic mortality record database.

2.2. Data collection and software

The registry follows the Manual of Standards for Cancer Registration, as followed by all MECC registries, to collect data for the Gharbiah residents diagnosed and/or treated in or outside the province [6]. Data is recorded using the World Health Organization ICD-03 coding. Case staging was completed based on SEER and then AJCC staging beginning in 2002 [7].

CanReg software, created by IARC, is the software used by the GPCR for data entry in English. CanReg version 3 was used until 2003 in which version 4 came out. The software creates a file for each new entry but does not always accurately identify duplicate cases. As the GPCR progressed, it was realized that Arabic names could be translated to several versions in English and thus duplicate registry records were created for the same cases. Additionally, medical records were not always complete, often lacking key information pertinent to cancer risk factors including occupation, accurate age, and residence. Paper mortality records were initially difficult to link to the cancer registry. Thus, the GPCR adopted the previously mentioned three methods to improve the data collection and quality of the registry.

2.3. Developments in Egypt introduced that improved data collection

2.3.1. Arabic name translation software

Medical records in Egypt are written in English, however, the names of patients are usually traditional Arabic names that can have many ways of spelling when translated to English. The spelling of names created problems initially for the GPCR because duplicate records may be created due to inconsistent translation of their names to English. In order to mediate this problem, the GPCR created a software program to assist in consistent translation of Arabic names and detect duplicates. The use of this software in conjunction with other demographic variables such as such as national ID number, age, address, topography of the tumor, and tumor morphology aided in the identification of duplicates. In order to evaluate the impact Arabic name translation software, data was obtained for the number of duplicates for each year in the study period.

2.3.2. National identification numbers

In Egypt, a national identification number and card, which contained demographic information, was in early stages of use when the registry began in 1999. In 2001, the national ID was made mandatory in the Gharbiah province for any resident of the province to receive health care benefits and treatment in any local hospital or clinic. Because the GPCR collects most of its information from the cancer centers and hospitals located in Gharbiah, the mandatory national ID made it possible for the registry to include more complete demographic information including accurate age/birth date, detailed address, gender, occupation, employer, and religion for almost all cases. Data was computed for the number of cases that had a national ID recorded in the GPCR. As an example of how using the national ID allowed for more complete information in a record, the number of cases that had an occupation recorded in the GPCR was also calculated.

2.3.3. Electronic mortality records

For a registry to be truly population-based, it must collect cancer cases from mortality records in addition to the data from medical centers. The proportion of cases from death certificate only (DCO), or cases who have no other evidence of tumor in other medical records, can indicate the quality of the registry and its collection process [10]. Too many cases from DCO can indicate that the collection and reporting processes of the registry are lacking and not being properly implemented [11]. The GPCR collects mortality records from the Ministry of Health, which used paper records when the GPCR first began. The use of paper records required manual search and analysis of mortality records to link to pre-existing cases in the registry. On January 1, 2004 all mortality records in Gharbiah became electronic and accessible to medical facilities. This electronic accessibility allowed the GPCR to perform electronic matching to existing cases in the GPCR. From the GPCR, the number of cases with mortality information in their record was obtained for each year since the inception of the registry. Additionally, the information recorded for basis of cancer diagnosis was compiled to describe the number of cases that came from DCO.

2.4. Data management and statistical analysis

Cancer registry data was collected from the GPCR and used to quantify the impact of the new procedures and methods. Due to increasing population and ability to detect and treat cancer, the number of cases in the registry increased each year. Thus, in order to better compare data between years, the number of cases was changed to a proportion of the total cases for each year. Information recorded regarding basis of cancer diagnosis was used to examine patterns in data sources. The sources were first

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