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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 (GCR), 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%.

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Brittney L. Smith: Original conception & design of study; analysis and interpretation of data; drafting and all revisions for intellectual content; final approval

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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.

Keywords

Cancer registration; Population-based; Data collection; Methods; Egypt; Low-and Middle-Income Countries

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 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.

Materials and Methods

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.

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.

Developments in Egypt introduced that improved data collection

A. 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.

B. 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.

C. 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.

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 grouped into one of the following four categories: (1) identification by death certificate only; (2) identification by non-microscopic information including clinical exam only, imaging, exploratory surgery, or specific biochemical/immunology tests; (3) microscopic including cytology/hematology, histology of metastases, and histology of primary tumor; and (4) identification method unknown. Then the four groups were tabulated.

Results

The GPCR had a total of 34,058 confirmed, non-duplicated cases from the Gharbiah Province for the years 1999–2007. Cancer of the breast, bladder, lung, colon, and brain are the 5 most common cancers in the province they represented 18.5%, 8.5%, 5.2%, 2.8%, and 3.1% of all cancer for all study years, respectively (Table 1).

The results from using the standardized Arabic name translation software showed an increase in the number and proportion of duplicate records detected in the GPCR. In 1999, 23.4% of cases had duplicate records detected, while 78.1% of cases had duplicates detected in 2007. From 1999 to 2007, there was an increase in the number of duplicates detected each year (Fig 1). Arabic name translation software was implemented in 2003. The total number of cases (the denominator) for each year differs from the total number of cases in the registry because those cases that reside outside of Gharbiah Province are eliminated after duplicate detection.

The use of the National ID in the medical facilities of the province increased the availability of demographic information in patient records. From 1999 to 2007 there was an increase in the number and proportion of cases that had a National ID recorded after the ID became mandatory. In 1999, 40% of cases had a national ID recorded, compared to 90% in 2007. The National ID includes detailed demographic information including occupation, and thus the number of cases that had an occupation recorded also increased. In 1999, 27% of cases had an occupation recorded compared to 89% in 2007. Specifically, the proportion of cases with a national ID recorded began to increase in 2001 and proportion of cases with national ID and occupation information became the same in 2004 (Fig 2).

The national ID became mandatory in Tanta and Gharbiah in 2001. Occupation was just one of the additional variables obtained from the National ID, and shown here to illustrate the increase in demographic information available with increased use of a National ID.

Reviewing the results of mortality records in the registry, showed that only 18% of cases had confirmed death in 1999, while 43% of cases had confirmed death in 2007. There was an increase in the proportion of cases that had a complete record including confirmed death, specifically from 2003 to 2004 when the MOH began using the electronic system for mortality records (Table 2).

Examining basis of cancer diagnosis showed that the number and proportion of cases diagnosed by non-microscopic examination increased from 9.2% in 1999, to 14.4% in 2007. Also, there was a decrease in the number of cases from DCO. The number and proportion from DCO, decreased from 9.8% in 1999 and decreased to almost half (4.7%) in 2007 (Table 3).

Discussion

Our study identified the following interesting observations. First, creating and using a software program to translate Arabic names to English led to significant increase in the proportion of duplicate cases. Second, utilizing the newly-introduced national Egyptian ID,

the GPCR was able to collect additional demographic information about the cases in the registry. Third, Egypt's transition to electronic mortality records enhanced the linkage of cancer cases from mortality records to cases existing in the registry. Finally, since the inception of the registry, the number of cases from DCO decreased significantly.

When Arabic names were translated to English, a variety of spellings limited the detection of duplicate records. By developing a standardized software program to detect pre-existing records, we were able to detect more duplicates and keep only one record per case. Following the first use of the program a sharp increase in the number of cases with one or more duplicates was observed. Detecting more duplicate entries allowed the GPCR to have a more accurate count of the number of cancer cases in the province. Analysis of quality indicators for cancer registries in LMICs noted that the identification of duplicate records is essential for calculating the true incidence rates [12]. In order to have reliable information, registries must represent, as close as possible, the true number of cancer cases in their respective populations [13].

Requiring a mandatory, standardized national ID to receive health care made a significant impact on the completeness of registry data. Using the national ID improved the quality of demographic information. Evaluation of cancer registries in LMICs found that data items such as residence, ethnic origin, religion, occupation and marital status are essential items for the quality of registries [14]. Complete background and demographic information about cases in a cancer registry allows health professionals, policy-makers, and researchers to have access to data that can be used for etiologic and prevention studies [10].

The implementation of electronic mortality records increased the efficiency of data collection and linkage between mortality and registry records, which resulted in higher quality and completeness of data collection. Utilization of electronic mortality records also reduced the workload of registry staff by eliminating the need for manual retrieval and searching through hard copies of mortality records or misidentifying registry cases. Previous studies examining cancer registries showed that the ability to accurately link records from several data sources helped in reducing the chance of recounting existing registry cases [15].

Advances in cancer diagnosis in Egypt, including the registry province of Gharbiah, by non-invasive biomarkers and/or imaging between 1999 and 2007 resulted in more diagnosis by non-microscopic means and less contributions of DCO [16]. Importantly, though, is that throughout 1999–2007 the proportion of cases diagnosed from microscopic means remained about 80% of all diagnoses. This rate is similar and possibly higher than the respective rates of diagnosis in registries from other LMICs data. An examination of the Uganda Cancer Registry in Kampala, Uganda showed that 68.9% of cases were confirmed microscopically [17]. Another study noted that only 3 of 16 African cancer registries examined reported microscopic verification at rates higher than 70% [12].

The decrease in proportion of records that were identified by DCO illustrates that more cancers are being identified in clinics or medical facilities. This could be attributed to more public awareness about cancer and increasing availability of diagnostic facilities and their utilization by health professionals[18]. Studies of cancer registries from LMICs in Africa

and Asia showed limited information on cause-specific mortality that limit the accuracy of cancer registration. On the other hand, registries in Latin America showed higher proportions of cases from DCO, indicating lower rates of valid information from clinical diagnostic facilities [12].

This study has several strengths. Having access to medical care and transportation facilities in all villages and most remote sites of the province diminished the chance of having cancer patients dying without being recorded in clinical or mortality records [19]. Certification of residential, occupational, and other demographic information in the national ID card by a government agency or work place ensured the quality of information obtained from this source in the cancer registry database. Using English for data entry allowed for better utilization of CanReg 3 and 4 software and identifying needs for improvement or adjustment, such as for the Arabic name spelling. Limited number and stability of the registry leaders and registrars minimized the instability of registration and identified needs for data quality improvement and evaluation of the impact of advances in clinical diagnosis and new databases of mortality and demographic information.

Overall some limitations of this study do exist. First, having more than 9 study years would have provided more years to assess the patterns and measure success in the registry, but the years currently used include the time periods in which the changes made an impact on the registry. Also, the capture rate of all cancers is low, as is common in LMICs. It is likely that the cancers captured in the GPBR does not depict the true rate of cancer in the region. However, the changes studied here that have made improvements on data collection and the advances the region continues to make in cancer screening and diagnosis will only increase the number of cases accounted for each year in the future.

Overall, locally-tailored methodological changes are important for increasing efficiency in the cancer registration systems in LMICs [20]. Specifically, methodologies made in Egypt and in the GPCR led to improved completeness and higher data quality that facilitated the use of data for epidemiologic and prevention research studies. Higher completeness of data and removal of duplicates led to increased ability to evaluate incidence including studies of incidence and regional variation of different cancers [19,21–25]; clinical and pathological subtypes of cancers [26–31]; and exploring unique cancer patterns of the country[32] and future cancer projections[33].

Conclusion

In summary, creating a software program to identify duplicate names, utilizing the electronic mortality database and newly-introduced IDs, and capturing the effect of diagnostic advances in the registry region led to improving the quality and completeness of the registry data. Future studies in Egypt should explore linking the database of the national IDs to the registry for epidemiologic studies considering the accuracy, richness, and frequent update of the national ID database. Other LMICs initiating or improving their population-based cancer registries could benefit from the experience of the Egyptian registry especially as global community development in LMICs is emerging with associated medical, public health, and technological advances.

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Highlights

- Use of software to translate names led to increased detection of duplicate cases
- Use of national ID led to increased collection of demographic information
- Use of electronic mortality records led to more complete records in the registry
- Decrease in DCO cases indicated better data collection in medical facilities

Fig. 1.
Percentage of total cases in the registry with one or more duplicates detected before and after use of Arabic Name Translation Software.

Fig. 2.
Proportion of complete data in the registry after mandatory use of the National ID.

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Table 1

Frequency of 5 of the most common cancers in the GPCR.

	Breast	Bladder	Lung	Colon	Brain	All other sites	Total
1999	632	337	184	93	95	2124	3465
2000	611	358	151	108	114	2181	3523
2001	642	309	192	90	96	2213	3542
2002	647	334	204	102	111	2211	3609
2003	689	294	189	84	93	2330	3679
2004	732	314	193	90	126	2462	3917
2005	746	317	202	132	141	2467	4005
2006	798	316	234	137	139	2468	4092
2007	811	317	238	143	140	2577	4226
Total	6308	2896	1787	979	1055	21033	34058

Table 2

Proportion of cases with mortality information recorded before and after implementation of electronic mortality records

Year	Total Mortality Recorded	
	<i>n=11,155</i>	%
1999	622	17.8
2000	783	22.2
2001	793	22.4
2002	1030	28.5
2003 ^a	773	21.0
2004	1525	38.9
2005	1828	45.6
2006	1962	47.9
2007	1839	43.5

^a Mortality records became electronic in 2003 in Egypt.

Table 3

Source for Basis of Cancer Diagnosis

Year	<i>a</i> DCO, % (n=197)		<i>b</i> Non- Microscopic, % (n=3715)		<i>c</i> Microscopic, % (n=28,114)		<i>d</i> Unknown, % (n=26)		Total Cases (n=34,058)
	n	%	n	%	n	%	n	%	
1999	338	9.8	318	9.2	2802	80.9	2	0.058	3465
2000	287	8.1	323	9.2	2911	82.6	2	0.057	3523
2001	206	5.8	330	9.3	3005	84.8	1	0.028	3542
2002	198	5.5	314	8.7	3096	85.8	1	0.028	3609
2003	234	6.4	350	9.5	3091	84.0	4	0.109	3679
2004	276	7.0	415	10.6	3220	82.2	6	0.153	3917
2005	204	5.1	548	13.7	3251	81.2	2	0.050	4005
2006	263	6.4	507	12.4	3318	81.1	4	0.098	4092
2007	197	4.7	610	14.4	3415	80.8	4	0.095	4226

^a DCO: identification of cancer by death certificate only;^b Non-microscopic: identification of cancer by clinical exam only, imaging, exploratory surgery, or specific biochemical/immunology tests;^c Microscopic: identification of cancer by cytology/hematology, histology of metastases, and histology of primary tumor; and^d Unknown: identification method unknown.