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Measuring the Effect of Improved Medical Facilities and Focused Training on Data Quality and Completeness: An Example from the Gharbiah Population-Based Cancer Registry, Egypt

Brittany Corley, MPH, **Mohamed Ramadan, MD**, **Brittney L. Smith, MPH**, **Ibrahim A. Seifeldein**, **Ahmed Hablas, MD**, and **Amr S. Soliman, MD, PhD**

Abstract

Cancer rates are increasing in low- and middle- income countries. There are a limited number of population-based cancer registries in Africa and the Egyptian population-based registry in Gharbiah is one of those registries. This registry has followed the standard international registration process and methods since 1999 and has been included in Cancer Incidence in Five Continents volumes IX and X. This article illustrates the reflection of improving medical care in the geographic region of the registry and focused training on enhancing the registry data. The registry area has seen advancement in medical care and cancer diagnostic facilities during the study period. The focused training included 8 different international training sessions over 8 different years for the registrars, administrators, and directors as well as continuing on-the-job training for other registry personnel. These improvements resulted in an overall 40% increase in nonmicroscopic diagnosis of hepatocellular carcinoma, as well as 20%, 10%, and 10% increases in microscopic diagnosis of pancreatic, brain, and lung cancers, respectively, over 9 years. An overall increase of 5% to 10% in subsite diagnosis was also seen for lung, colon, brain, bladder, and breast cancers for the same 9 years. An increase of 3% in grading was seen for solid tumors while 11% was seen for lymphoma. This study showed that low- and middle- income countries can observe higher data quality for cancer registries with improvement in medical care and focused training.

Keywords

cancer registry; Egypt; low- and middle-income countries; training

Introduction

Cancer is a global health problem with anticipated increase in incidence and a notably increased burden of cancer-related mortality in low- and middle-income countries (LMICs) in the next 2 to 3 decades.[1,2] Cancer registries provide valuable objective information about the burden of cancer and effectiveness of prevention interventions in populations.[3] Cancer incidence rates are increasing in Africa because of increased life expectancy and

Address correspondence to Amr S. Soliman, MD, PhD, Department of Epidemiology, College of Public Health, University of Nebraska Medical Center, 984395 Medical Center, Omaha, NE 68198-4395. Telephone: (402) 559-3976. Fax: (402) 559-7259. amr.soliman@unmc.edu.

epidemiologic and nutritional transitions.[4] The lowest international coverage of population-based cancer registries is in Africa (1%) compared to 25% to 100% in other continents.[5]

Egypt's only population-based registry was created by the Middle East Cancer Consortium (MECC) through the National Cancer Institute (NCI) in the Gharbiah province in the center of the Nile Delta region in 1998.[6] The Gharbiah Population-Based Cancer Registry (GPCR) has been collecting incident information about all cancer cases among the approximately 4 million residents of the province who are diagnosed inside and outside of the province, and registry data have been included in Cancer Incidence in Five Continents (CI5) volumes IX and X.[7,8] The registry follows the Manual of Standards for Cancer Registration, as followed by all MECC registries, to collect data from clinics, pathology labs, imaging centers, and health bureaus in Gharbiah through an active registration process.[9] Validation and quality control studies of the data have been conducted by the International Agency for Research on Cancer (IARC), Surveillance Epidemiology and End Results (SEER) group of NCI, and MECC, and showed high and improved data quality.[7,8]

In addition to the standard practice used by good quality cancer registries, the GPCR has developed additional methods to improve the quality of the registry. Standard practice registry collection has been described by IARC in detail.[10] Factors that added to improving the data quality of the GPCR included availability of medical and diagnostic facilities in the province, medical background of the registrars, and increased cancer awareness in the geographic area of the registry.[11,12]

Background

Gharbiah Population-Based Cancer Registry

The Gharbiah province is about 60 miles north of Cairo. The capital of the Gharbiah province is Tanta city which has one of the major cancer centers in Egypt. The GPCR is located in Tanta and was founded in 1998 by the US NCI as part of the MECC.[6] The majority of cancer cases in the registry are obtained from the Tanta Cancer Center, Tanta University Hospital, the Gharbiah Cancer Society, and the 5 major pathology laboratories of the province. A limited number of cases (about 10%) are obtained from the Mansoura University Hospitals, insurance hospitals, the National Cancer Institute of Cairo University, and death certificate records. The registry included information on all residents who were diagnosed or treated for cancer, either within or outside the province.

The cancer registry data are formatted using the World Health Organization International Classification of Diseases for Oncology, third edition (ICD-O-3) coding.[13] Case staging has been completed in 2 ways. From 1999–2007, the stage information was based on the SEER staging[14] and from 2003–2007, the staging of breast cancer cases was coded based on the American Joint Committee on Cancer (AJCC) staging.[15]

Improvements in Medical Care

The first improvement that affected the GPCR was an increase in the number of medical and diagnostic facilities over the 9 years of data collection. During that period, the majority of cases were acquired from the Tanta Cancer Center, the Gharbiah Cancer Society, and the

Tanta University Hospitals. However, over the course of data collection for the registry, the number of data sources has included 10 hospitals and 62 departments and subspecialties. This showed an increase of 2 hospitals and 4 departments over the 9 years of the registry.

Training of Registrars

The second improvement that affected the GPCR was the training of registrars over the 9 years of data collection. The registrars employed by the GPCR were typically medical oncologists of the Tanta Cancer Center. At the beginning of the registry, there were 3 registrars, a medical oncologist, a pathologist, and a surgical oncologist. As the registry grew, so did the number of registrars. By the end of 2007, there were 7 registrars, 6 of whom were medical oncologists and 1, a pathologist.

The domestic and international training sessions focused on principals of cancer registration, purposes of registration, definition and data collection in cancer registries, data classification and coding guidelines, data quality and completeness, and CanReg software, with a focus on data entry analysis and management. The training sessions, hands-on training, and quality control and validation training were delivered by experts from University of California—Irvine (UC-Irvine), Emory, IARC, and the SEER Program at NCI.

Emphasis on training of registrars expanded significantly over the study period. Initial training in Egypt was provided by UC-Irvine in 1998 and was for the registrars, administrators, and hospital directors. This same group of people also completed training in Egypt by Emory University annually from 2001–2003. The training was followed by annual training on data software and data management from 2007–2010.

The training resulted in creating a manual for the process of data abstraction and entry. The manual included a description of coding and staging as well as possible questions that might arise during the abstraction and registration process. Besides this manual, all other registry personnel were offered continuing on-the-job training as well as cancer registration training courses arranged by the Egyptian Ministry of Health.

Throughout 1999–2007, medical facilities increased significantly in Gharbiah and several focused training workshops were provided to the registry staff and registrars. Therefore, this study aimed to quantify the effect of improved medical facilities and the focused training on data quality and its completeness of the GPCR.

Methods

The study originated from clinical impressions of the registry team that improvements made within both the regional medical facilities and registry training resulted in better quality of the registry data. Therefore, variables that could test this hypothesis were defined. These variables included microscopic diagnosis, subsite specification, and tumor grading. This was followed by retrieval of data for the selected variables for the entire period of the registry (1999–2007). The methods of diagnosis for hepatocellular, pancreatic, lung, and brain cancers were divided into microscopic and nonmicroscopic diagnoses. For lung, colon, brain, bladder, and breast cancers, subsite specification was then determined as known or

unknown. Clinical diagnosis of these cancer sites is becoming more prevalent and necessary, when possible, to avoid complications of unnecessary biopsies that may induce complications. Tumor grading was defined as present or missing/unknown. The cancers listed above were not the leading cancers in our registry; however, these cancers were the best sites for reflecting the improvement in medical facilities and training. Proportions of cases based on the variables of the chosen criteria relative to all cases in the registry were calculated annually and tabulated.

Data Collection, Management and Software

All data used in this manuscript were abstracted from the GPCR. The registry started by using CanReg 3 until 2003 then switched to CanReg 4. CanReg is the software developed by IARC and made available in English format for all data entry and retrieval in LMICs. Cases in this analysis were obtained from 1999, the first year of registry, until the last year of complete registry data in 2007. Complete data after 2007 were not available because of the discontinued MECC funding since 2011 and the current continuation of the registry through local financial resources at a slow pace. As the first year of the registry, 1999 was used as the baseline from which all changes were tested.

To evaluate the impact of the improvement in medical facilities and focused training, data were obtained to examine the change in the rate of microscopic verification of hepatocellular, pancreatic, lung, and brain cancers, subsite specification of lung, colon, brain, bladder, and breast cancers, as well as tumor grading for all cancers. These criteria were chosen because of their reliability in reflecting improvements in documenting accurate cancer diagnosis in both medical facilities and the cancer registry. Treatment information was excluded from analysis because it is considered an optional data item in MECC and registries from other developing countries, as reported in CI5-IX and CI5-X.[7,8] Also, treatment was only included in the last 5 years of this registry data set (2003–2007).

To test for a linear trend within the data a χ^2 test for trend was conducted using SPSS 22 (Release 22.0, IBM, Armonk). Test results were considered to show a significant linear trend when a P value of less than .05 was present.

Results

Data were abstracted from a total of 38,773 cancer cases. Of these cases, only 34,038 were in residents of the Gharbiah province from 1999–2007. The total number of cases recorded by the GPCR has increased since 1999. In 1999, there were 3,465 cases of cancer and in 2007 there were 4,226 cases of cancer from Gharbiah. Over the 9 years of our study, 39.4% of cancer cases were male, 40% of cases lived in urban areas, and 82.6% of cases had cancer microscopically confirmed. The demographic data showed no changes within the 9 years of the study.

Table 1 shows the change in percentage of cases microscopically or nonmicroscopically diagnosed for hepatocellular carcinoma, pancreatic, brain, and lung cancers. From 1999–2007, the percentage of nonmicroscopic diagnoses of hepatocellular carcinoma increased from 38% to 74%, (P = .001) while microscopic diagnoses decreased from 42% to 20%. For

pancreatic, brain, and lung cancers, the percentage of nonmicroscopic diagnoses decreased from 61% to 54% ($P = .05$), 14% to 7% ($P = .80$), and 10% to 5% ($P = .01$), for the 3 cancers, respectively, while microscopic diagnoses increased from 21% to 41%, 59% to 67%, and 76% to 86%, for the 3 cancers, respectively.

In Table 2, the change in subsite diagnosis is illustrated for lung, colon, brain, bladder, and breast cancers. The change showed an increase from 58% to 65% ($P = .107$), 73% to 85% ($P = .014$), 64% to 66% ($P = .793$), 51% to 55% ($P = .207$), and 60% to 74% ($P = .001$), respectively.

Table 3 highlights the change in tumors with graded information over the study period. Grading of solid tumors showed a slight increase from 74% to 77% ($P = .001$). The change for lymphoma and leukemia grading increased from 4% to 15% ($P = .001$).

Discussion

This study highlighted the following interesting observations. First, the study showed an increase in microscopic diagnoses of pancreatic, brain, and lung cancers during the study period. However, the microscopic diagnoses for hepatocellular carcinoma decreased. Second, the study showed a uniform increase in subsite diagnoses for lung, colon, brain, bladder, and breast cancers. Third, the study showed an increase in tumor grading for both solid and hematopoietic cancers. Overall, no additional changes were observed in the registry for other cancer sites. Better data quality likely resulted from improved training among the physicians who diagnose cancer and the registry staff who feed the data into the GPCR, as reported in comparing diagnostic ability of trained vs untrained professionals.[16]

Pancreatic, brain, and lung cancers have seen significant improvement in diagnostic imaging and biopsy verification, globally and in Egypt.[17] The importance of these cancers having histologic verification has been described in several studies,[18–23] most notably by Bray and Parkin[21,22] as a reflection of importance of verification for validation of the diagnosis. In the region of the registry, the number of pathology labs increased from 5 to 10 during the 9-year registry period. This doubling of pathology labs in Gharbiah may have resulted in fewer number of days needed for receiving the pathologic examination results and quicker reporting of histologic verification.

The decrease in microscopic diagnoses for hepatocellular carcinoma is due to the recommendation of MECC during the study period for standardizing the diagnosis of hepatocellular carcinoma by α-fetoprotein (AFP) in MECC registries. The implementation of this standardization had been shown by the increase in nonmicroscopic screening rates in clinical practice in the study population.[24]

The improvement in subsite diagnosis could be a result of better data collection by registry personnel who are medical oncologists and who received the focused training described above. Subsite diagnosis is a place where missing or unknown values are common.[16] Subsite diagnosis may be a reflection of improved accuracy of recording the information in the medical records, as a result of training, rather than increasing data quality of the registry.[21,25] This finding supports our assumption that improvement in subsite diagnosis

could be a reflection of improved cancer diagnostic facilities in Egypt and/or effect of the focused training of the medical oncologists/registrars.

The improvement in tumor grading could be a reflection of better engagement of the pathologists in Gharbiah and their improved reporting of grading in pathology reports. Grading of lymphoma and leukemia has seen drastic improvements internationally.[26,27] Targeted therapy and other treatment of graded lymphoma and leukemia are more precise than treatment of the same tumors without grading information.[28] Grading is another example of where having incomplete data may be more of a reflection of the efficiency of the medical facilities rather than the training of the registrars.[25]

This study has a few strengths. The documentation of training offered to personnel and the stability of the same registry staff were important. The compatibility between CanReg 3 and CanReg 4 allowed for importing the data and maintenance of the data records. Furthermore, the existence of high quality medical care and diagnostic facilities in this population enhanced the chance of capturing changes in diagnostic and pathologic diagnosis of cancers in this registry.

This study also has limitations. One limitation is that, while the 9-year period was helpful in observing the changes in the registry, a longer period could have enhanced the detection of trends. Other limitations include the lack of availability of data on follow-up treatment and the availability of AJCC staging from 2002 not since the beginning of the registry. Additionally, there is no documentation that the knowledge of the registrars increased during the study years due to training.

While being a limitation of the study, we believe the AJCC staging addition in 2002 had minimal effect on our study. The AJCC staging was only added for breast cancer from 2002. Therefore, our reported sites other than the breast did not include SEER and AJCC and no differences in results were observed. For breast cancer, the AJCC staging is primarily for optimizing clinical diagnosis and related treatment and is not part of the routine registry information. Therefore, we do not believe that addition of the AJCC has improved the registry information but might have improved clinical diagnosis, including staging and subsites, and treatment.

In summary, this study showed an increase in microscopic diagnoses of pancreatic, brain, and lung cancers in the GPCR. However, microscopic diagnoses for hepatocellular carcinoma decreased. The study also showed a uniform increase in subsite diagnosis of lung, colon, brain, bladder, and breast cancers. The increase in tumor grading of both solid and hematopoietic cancers was observed. The advances in diagnosis and classification of the GPCR data could be due to the focused training offered to the registrars and the general improvement in clinical diagnosis of cancer in the study population. While it is true that good-quality registries might be a reflection of better data collection, the chosen variables in our study reflect better improvement in pathologic and clinical diagnosis rather than data collection.

Future studies should focus on evaluating the changes in professional education of both registrars and oncologists in this registry and its region to estimate their possible

contribution to the listed improvements. Future studies should also evaluate the effect of training and improvement in clinical diagnostic facilities on data quality of registries in the MECC region and other LMICs.

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References

1. Bray F, Jemal A, Grey N, Ferlay J, Forman D. Global cancer according to the human development index (2008–2030): A population-based study. Lancet Oncol. 2012; 13(8):790–801. [PubMed: 22658655]
2. Maule M, Merletti F. Cancer transition and priorities for cancer control. Lancet Oncol. 2012; 13(8): 745–746. [PubMed: 22846827]
3. Dos Santos Silva, I., editor. Cancer Epidemiology: Principles and Methods. Lyon, France: International Agency for Research on Cancer; 1999. The role of cancer registries; p. 385-403.http://www.iarc.fr/en/publications/pdfs-online/epi/cancerepi/CancerEpi-17.pdf [Accessed December 10, 2014]
4. Jemal A, Center MM, DeSantis C, Ward EM. Global patterns of cancer incidence and mortality rates and trends. Cancer Epidemiol Biomarkers Prev. 2010; 19(8):1893–1907. [PubMed: 20647400]
5. Ferlay, J.; Shin, H.; Bray, F.; Forman, D.; Mathers, C.; Parkin, DM. GLOBOCAN 2008, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10. Lyon, France: International Agency for Research on Cancer; 2010. p. 29
6. Freedman, LS.; Edwards, BK.; Ries, LAG.; Young, JL., editors. Cancer Incidence in Four Member Countries (Cyprus, Egypt, Israel, and Jordan) of the Middle East Cancer Consortium (MECC) Compared with US SEER. Bethesda, MD: National Cancer Institute; 2006.
7. Curado, MP.; Edwards, B.; Shir, HR., et al., editors. Cancer Incidence in Five Continents. Vol. X. Lyon, France: International Agency for Research on Cancer; 2013.
8. Curado, MP.; Edwards, B.; Shin, HR., et al., editors. Cancer Incidence in Five Continents. Vol. IX. Lyon, France: International Agency for Research on Cancer; 2007.
9. Ministry of Health and Population, Egypt. Cancer in Egypt, Gharbiah: Triennial Report of 2000–2002 Gharbiah Population-Based Cancer Registry. Egypt: Middle East Cancer Consortium; 2007.
10. Bray, F.; Znaor, A.; Cueva, P., et al., editors. Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings. Lyon, France: International Agency for Research on Cancer; 2014.
11. Al Tehewy M, Salem B, Habil I, El Okda S. Evaluation of accreditation program in non-governmental organizations' health units in Egypt: Short-term outcomes. Int J Qual Health Care. 2009; 21(3):183–189. [PubMed: 19439444]
12. World Health Organization. [Accessed December 12, 2014] Country Cooperation Strategy for WHO and Egypt: 2010–2014. http://applications.emro.who.int/docs/CCS_Egypt_2010_EN_14481.pdf#sthash.hR9HG7xd.dpuf
13. World Health Organization. International Classification of Diseases for Oncology (ICD-O). 3. Geneva, Switzerland: World Health Organization; 2013. 1st revision
14. Surveillance Epidemiology and End Results Program. ICD-O-3 SEER site/histology validation list. SEER program quality control section. Updated December 4, 2009
15. American Joint Committee on Cancer. AJCC Cancer Staging Manual. 7. New York, NY: Springer Science + Business Media LLC; 2010.
16. Ljung B, Drejet A, Chiampi N, et al. Diagnostic accuracy of fine-needle aspiration biopsy is determined by physician training in sampling technique. Cancer Cytopathology. 2001; 93(4):263–268. [PubMed: 11507700]

17. Czernin J, Allen-Auerbach M, Schelbert HR. Improvements in cancer staging with PET/CT: Literature-based evidence as of September 2006. J Nucl Med. 2007; 48(suppl 1):78S–88S. [PubMed: 17204723]
18. Bernards N, Creemers GM, Huysentruyt CJ, et al. The relevance of pathological verification in suspected pancreatic cancer. Cancer Epidemiol. 2015; 39(2):250–255. [PubMed: 25670054]
19. Berrino F, De Angelis R, Sant M, et al. Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995–99: results of the EUROCARE-4 study. Lancet Oncol. 2007; 8(9):773–783. [PubMed: 17714991]
20. Gatta G, Ciccolallo L, Capocaccia R, et al. Differences in colorectal cancer survival between European and US populations: The importance of sub-site and morphology. Eur J Cancer. 2003; 39(15):2214–2222. [PubMed: 14522381]
21. Bray F, Parkin DM. Evaluation of data quality in the cancer registry: principles and methods. Part I: Comparability, validity and timeliness. Eur J Cancer. 2009; 45(5):747–755. [PubMed: 19117750]
22. Parkin DM, Bray F. Evaluation of data quality in the cancer registry: principles and methods. Part II: Completeness. Eur J Cancer. 2009; 45(5):756–764. [PubMed: 19128954]
23. Bhurgr Y, Hasan S, Bhurgri A. Comparability and quality control in cancer registration; Karachi (data monitoring 1995–2001). J Pakistan Medical Assoc. 2002; 52(7):301–307.
24. Youns MM, Wahab Abdel Hady A, Abdel Hassan ZA, Attia MS. Serum talin-1 is a potential novel biomarker for diagnosis of hepatocellular carcinoma in Egyptian patients. Asian Pac J Cancer Prev. 2013; 14(6):3819–3823. [PubMed: 23886189]
25. Leitzmann MF, Rohrmann S. Risk factors for the onset of prostatic cancer: age, location, and behavioral correlates. Clin Epidemiol. 2012; 4:1–11. [PubMed: 22291478]
26. Soliman, A.; Boffetta, P. Cancer Incidence in Four Member Countries (Cyprus, Egypt, Israel, and Jordan) of the Middle East Cancer Consortium (MECC) Compared with US SEER. Bethesda, MD: National Cancer Institute; 2006. Lymphoma and leukemia. NIH Pub. No. 06-5873
27. Herzog CM, Dey S, Hablas A, et al. Geographic distribution of hematopoietic cancers in the Nile delta of Egypt. Ann Oncol. 2012; 23(10):2748–2755. [PubMed: 22553197]
28. Ludwig JA, Weinstein JN. Biomarkers in cancer staging, prognosis and treatment selection. Nature Reviews Cancer. 2005; 5(11):845–856. [PubMed: 16239904]

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Table 1

Percentages of Microscopic and Nonmicroscopic Basis of Diagnosis in the Gharbiah Population-Based Cancer Registry During 1999–2007

	Hepatocellular Carcinoma †									
	1999	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	
Hepatocellular carcinoma, nonmicroscopic (%)	38	39	42	46	53	57	71	67	74	$P = .001$ **
Hepatocellular carcinoma, microscopic (%)	42	38	41	40	28	29	24	19	20	
Hepatocellular carcinoma, other * (%)	20	22	18	14	19	14	5	15	5	
	Pancreatic Cancer †									
	1999	2000	2001	2002	2003	2004	2005	2006	2007	
Pancreatic cancer, nonmicroscopic (%)	61	56	56	57	56	56	56	48	54	$P = .05$ **
Pancreatic cancer, microscopic (%)	21	29	41	40	38	34	42	47	41	
Pancreatic cancer, other * (%)	18	15	3	4	6	10	2	5	5	
	Brain Cancer †									
	1999	2000	2001	2002	2003	2004	2005	2006	2007	
Brain cancer, nonmicroscopic (%)	14	9	13	8	9.9	8	5	6	7	$P = .80$
Brain cancer, microscopic (%)	59	69	63	68	63	61	68	66	67	
Brain cancer, other * (%)	27	22	25	24	28	31	27	28	27	
	Lung Cancer †									
	1999	2000	2001	2002	2003	2004	2005	2006	2007	
Lung cancer, nonmicroscopic (%)	10	11	8	8	6	6	9	6	5	$P = .01$ **
Lung cancer, microscopic (%)	76	79	85	87	90	86	85	87	86	
Lung cancer, other * (%)	14	10	7	5	4	8	6	8	8	

* Other includes those with diagnosis of death certificate or unknown.

** Statistically significant.

† χ^2 test for trend was conducted on microscopic diagnosis versus all others.

Table 2

Percentages of Subsite Specification in the Gharbiah Population-Based Cancer Registry During 1999–2007

Year	Lung Cancer (P = .107), %	Colon Cancer (P = .014*), %	Brain Cancer (P = .793), %	Bladder Cancer (P = .207), %	Breast Cancer (P = .001*), %
1999	58	73	64	51	60
2000	60	71	64	51	66
2001	61	87	68	61	70
2002	68	88	66	58	69
2003	65	89	69	52	70
2004	71	88	69	62	68
2005	69	79	65	56	71
2006	62	85	66	56	73
2007	65	85	66	55	74

*Statistically significant ($P < .05$).

Table 3

Percentages of Tumor Grades other than Unknown in the Gharbiah Population-Based Cancer Registry from 1999–2007

Year	Solid Tumor (P = .001*), %	Lymphoma and Leukemia (P = .001*), %
1999	74%	4%
2000	74%	6%
2001	76%	6%
2002	78%	12%
2003	78%	12%
2004	78%	9%
2005	78%	11%
2006	79%	14%
2007	77%	15%

*Statistically significant.