ORIGINAL ARTICLE

Audit of a nationwide pathology-based cancer registry in Iran

Kazem Zendehde [1,2,*], Zahra Sedigh [1], Jaleh Hassanloo [1], Azin Nahvijou [1]

ABSTRACT

Background: Cancer registries are important infrastructure for cancer control programs. However most developing countries lack population based cancer registry. In Iran there cancer incidence is estimated based on pathology-based cancer registry. In this study we evaluated results of the nationwide pathology-based cancer registry in Iran.

Materials and Methods: We compared age-standardized incidence rate (ASRs) of all cancers combined among male and female from 2004 to 2006 for the entire country and stratified by 30 provinces. In addition, we compared ASRs of all cancer combined and six common cancers from pathology-based cancer registry with the results of population-based cancer registry conducted in five provinces including Tehran, Aradbil, Kerman, Golestan, and Semnan provinces. Ratio of pathology-based to population-based cancer registries in these provinces perceived as the completeness of pathology-based cancer registry.

Results: We found that ASRs among men and women increased from 2004 to 2006. However, the increasing trend was not consistent for all 30 provinces; ASRs increased, decreased on remained stable in different provinces. Completeness of pathology-based cancer registry was about 58% and 64% for men and women, respectively. Among the other, the completeness was extremely low for lung (26%) and esophageal (53%), and stomach (54%) cancers among male and for stomach (54%) and ovary (0.68%) among female.

Conclusion: Pathology-based cancer registry underestimates the cancer incidence and cannot be a reliable source for policy making and research. Inclusion of other sources such as death registry and establishment of population-based cancer registry is necessary. We suggest promoting regional population-based registries using standard methods in Iran and other developing countries.

Keywords: cancer registry, pathology-based, population-based, Iran.

زمینه و هدف: ثبت سرطان یکی از مهمترین زیر ساختهای مورد نیاز برای استقرار برنامه کنترل سرطان می باشد. با این حال ثبت سرطان جمعیتی در بیشتر کشورهای در حال توسعه وجود ندارد. در ایران میزان های بروز سرطان بر اساس ثبت سرطان مبتنی بر پاتولوژی تخمین زده می شود. در این مطالعه نتایج این ثبت سرطان پاتولوژی کشوری مورد بررسی قرار گرفت.

مواد و روشها : در این مطالعه میزان بروز استاندارد شده سنی تمام سرطانها در مردان و زنان از سال ۱۳۸۳ تا ۱۳۸٦ برای کل کشور و برای ۳۰ استان کشور مورد مقایسه قرار گرفت. بعلاوه میزان بروز تمام سرطانها و سرطان شایع را بین ثبت سرطان پاتولوژیک و جمعیتی در ۵ استان کشور شامل تهران، اردبیل، کرمان، گلستان، و سمنان مقایسه شد. نسبت میزان بروز ثبت سرطان پاتولوژی و ثبت سرطان جمعیتی به عنوان معیار کم شماری داده های ثبت سرطان جمعیتی در نظر گرفته شد.

یافته ها: میزان بروز سرطان هم در مردان و هم در زنان از سال ۲۰۰٤ تا ۲۰۰٦ افزایش یافته بود، هر چند روند افزایشی برای تمام ۳۰ استان مشاهده نشد. در استانهای مختلف، میزان بروز افزایش، کاهش یافته و یا بدون تغییر بود. میزان کامل بودن ثبت پاتولوژی برای سرطانهای مردان و زنان به ترتیب ۵۸ و ٦٤ درصد بود. در مردان میزان کامل بودن موارد سرطانی برای سرطان ریه ۲٦ درصد، سرطان مری ۵۳ درصد، و برای سرطان معده ۵٤ درصد بود. همچنین در زنها میزان کامل بودن برای سرطان معده ۵٤ درصد و سرطان تخمدان ٦۸ درصد بود.

نتیجه گیری : تخمین میزان بروز بر اساس ثبت سرطان پاتولوژی بسیار کم تر از میزان واقعی میزان می باشد و نمی تواند به عنوان یک منبع قابل اعتماد برای سیاستگزاری و انجام تحقیقات اپیدمیولوژیک مورد استفاده قرار گیرد. پیگیری ثبت سرطان جمعیتی منطقه ای بر اساس روش های استاندارد به عنوان یک ضرورت مهم توصیه می شود.

واژه های کلیدی: ثبت سرطان مبتنی بر پاتولوژی، ثبت سرطان جمعیتی، ایران

1. Cancer Research Center, Tehran University of Medical Sciences, Iran.
2.Department of Medical Epidemiology and Biostatistics, Karolinska Institute, Sweden.

*** Correspondence:**
Kazem Zendehdel, MD, PhD
Cancer Research Center, Cancer Institute, Tehran University of Medical Sciences
End Keshavarz Bulvar, Tehran , 1419733141, Iran
P.O. Box: 13145-158
Email: Kzendeh@tums.ac.ir

Introduction

A Burden of non-communicable diseases has inflated remarkably both in high-income and middle-income countries including Iran,[1] where cardiovascular diseases, injuries, and cancer are the most common causes of death respectively.[2]

Population-based cancer registries play important role in the design and monitoring of the cancer control programs, including conduct of epidemiological research, monitoring and evaluation of screening programs, follow-up of cancer patients and evaluation of prognostic measures and resource allocation. While up to 70 percent of the cancers occur in the low- and middle-income countries, unfortunately the establishment of population-based cancer registries is not appreciated in these countries.[3-4] While the most cancer registries established in high-income countries, few populations in the low- and middle-income countries are covered by cancer registries. For instance, coverage of cancer registries in US, Australia and New Zealand, European Union, and Japan is 99%, 86%, 57%, 35%, respectively. However, only 21%, 11%, and 8% of countries in the South-Central American, Africa and Asia are, respectively, covered by cancer registries.[5] Inadequate attention to establishment of high quality cancer registry in the latter regions could be due to lower priority of cancer control program, financial constraints, weak infrastructure and expertise. However, several countries has launched cancer registries that could not reach to a reasonable level of validity and completeness, necessary attributes for any cancer registry.[6-8] These registries covers mainly pathology records and lacks other sources of population-based cancer registry, including i.e death records, hospital records, clinical data, etc.[7] In addition, a few registries tried to collect more data from death registries or hospitals, but could not reach to a reasonable saturation and meet IARC standards for publication in the IARC monograph "Cancer in Five continents". However, level of completeness and validity of these registries were not, so far, scrutinized.

In this study we aimed to evaluate the completeness of pathology-based cancer registration in Iran.

Methods

During the last decade, several cancer registry initiatives have launched in IR. of Iran, including a national pathology-based cancer registry [9] and few population-based cancer registries.[10] However, due to insufficient validity and completeness, data from these registries was not so far published on the famous IARC monograph. There are proposals to promote cancer registration programs and establish a nationwide population-based registration system in Iran. Before launching the new system, it is important to evaluate strength and limitation of the current registration system and try to build the new initiatives based on readily available experience. In this study, we evaluate completeness of Iranian national pathology-based cancer registry program for all cancer types combined and for common cancer subtypes.

History and current status of cancer registration in Iran has been recently published.[10] Cancer Office at the Center of Disease Control (CDC), Ministry of Health and Medical Education has established national pathology-based cancer registry program, in which data all pathology center report cancer cases to the regional office in their province. Central cancer office at CDC, then, compiles and analyze the collected data and publish annual report of the cancer incidence in the country. Three reports in 2004, 2005, and 2006 have been, so far, published.

In addition to the national pathology-based registry, a few regional population-based cancer registries has been established in different geographical regions including Ardabil, Kerman, Golestan, Tehran and Semnan provinces. Theses registries actively abstract and analyze cancer data from different data sources and publish regional reports of cancer incidence rate. These registries are independently administered by research groups/centers in the corresponding regions.

Results from these registries were published in peer reviewed journals or locally as a report of the regional cancer registry. Except the reports from Golestan province in which annual reports were published for four consecutive years from 2004 to 2007, rest of the population-based registries were based on the retrospective survey of cancer data from different data sources and for specific periods, i.e. Tehran (1997-2001), Kerman (1996-2000),

Semnan (1998-2002), and Golestan (2005-2007), and Ardabil (1996-1999 and 2004-2006).[11-12]

Statistical analyses

We compared the age-standardized incidence rates (ASR) reported based on pathology-based cancer registry from 2004 through 2006. This comparison was stratified by sex and geographical region. Stability and increase in the incidence rates over time were indications for successful registration practice.

In addition, we compared ASRs of pathology-based registries with the corresponding rates reported from five population-based cancer registries, assuming that the completeness of the latter registries are convincing. We compared the ASRs for all cancer types combined and for some common cancer sites including stomach, bladder, prostate, colorectal, lung, and esophageal cancers among male and breast, colorectal, stomach, esophageal, lung, thyroid, and ovary cancers among female. We divided the average ASRs of pathology registry to the average ASRs of population registries for all cancers combined and for site specific cancer types. Since pathology-based cancer registry completed by time, we used the latest report of the pathology-based registry (2006) for comparisons.

Age-standardized incidence rates between 2004 and 2006 for the entire country showed increasing pattern

Results

in both men and women. It increased from 95.4 (2004) to 117.3 (2006) per 100,000 among male and from 83.4 (2004) to 102 (2006) per 100,000 for women (**Table 1**). In 2006, the highest ASRs were observed in Khoasan_Rezavi (ASR 144.4), Isfhan (ASR 127.2), and Kordestan (ASR 114.5) provinces for male and in Khoasan_Rezavi (ASR 123.3), Isfhan (ASR 115.3), and Mazandaran (ASR 104.6) provinces for female. We observed the lowest incidence rates in Sistan_Baluchestan (ASRmale 32.8, ASRfemale 30.5), North_Khorasan (ASRmale 40.2, ASRfemale 34.2), and East_Azarbaijan (ASRmale 50, ASRfemale 35.5) provinces.

Although ASRs of all cancer types combined increased from 2004 to 2006 in the entire country, increasing pattern was not consistent for all provinces. Although it increased from 2004 to 2006 in some provinces like Hamadan, Isfahan, Sistan, and Tehran provinces, other provinces showed no changes or decreasing pattern over time. For instance, in the East Azarbaijan, ASRs among male decreased from 96.7 in 2004 to 50.1 per 100,000 in 2006, and among female ASR decreased from 67.9 (2004) to 35.5 per 100,000 (2006). We found no clear pattern in some regions like Ardabil province, where ASR of all cancer types combined dropped from 113.8 per 100,000 in 2004 to 74.0 in 2005, but inflated again to 113.2 in 2006.

In comparison to the population-based cancer registries, 58% and 64% of cancer cases were registered by pathology-based registry in male and female, respectively (**Table 2, Table 3**). The coverage was considerably low in lung (26%), esophageal (53%), and stomach (54%) cancers among male and also in stomach (54%) and ovary (68%) cancers among women. Pathology-based cancer registry showed more than 90 percent coverage for bladder cancer (92%) among male and relatively convincing coverage for thyroid (84%), colorectal (80%), and breast (78%) cancers among female. **Figure 1** and **Figure 2** illustrates the magnitude of underestimation in the pathology-based cancer registry for common cancer in male and female, respectively.

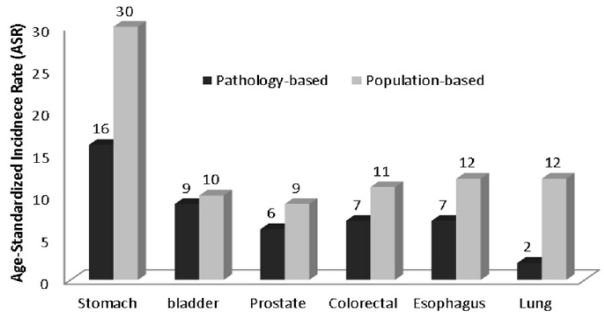

Figure 1: Comparison of ASRs of male common cancers based on pathology- and population-based registries in Iran.

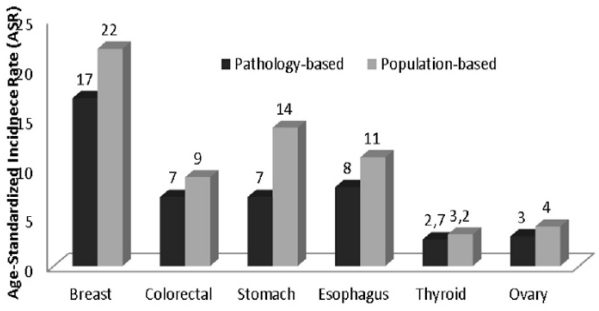

Figure 2: Comparison of ASRs of female common cancers based on pathology- and population-based cancer registries in Iran.

Table 1. Age-standardized incidence rates (ASRs) for all cancer types combined among male and female reported in the Iranian national pathology-based cancer registration in 2004, 2005, 2006.

Provinces	Population size	No. of pathology centers*	Male ASR			Female ASR		
			2004	2005	2006	2004	2005	2006
Ardabil	1224492	12	113.8	74.0	113.2	94.8	56.0	89.8
Bushehr	897020	10	58.1	70.0	70.2	52.8	63.3	71.2
Chaharmahal B.	855649	7	83.0	85.8	105.1	108.3	70.2	69.8
East Azarbayjan	3598916	34	96.7	59.0	50.1	67.9	42.4	35.5
Fars	4279766	61	70.3	87.3	95.2	61.8	76.3	89.6
Ghazvin	1131257	18	100.1	94.7	103.9	80.0	94.9	-
Gilan	2377531	25	85.1	118.2	112.3	61.3	104.8	95.3
Golestan	1609331	23	78.6	75.1	98.9	70.1	70.3	81.4
Hamadan	1696549	21	72.9	89.1	105.9	48.2	74.1	88.7
Hormozgan	1362791	12	45.0	40.1	47.4	42.0	38.5	51.7
Ilam	543729	4	64.3	43.0	80.0	72.0	41.0	71.1
Isfahan	4599172	64	109.7	112.7	127.2	92.3	104.6	115.3
Kerman	2605967	35	74.9	71.4	85.8	72.7	61.8	82.7
Kermanshah	1870244	14	92.7	97.4	92.4	77.7	80.6	80.7
Khorasan North	808339	-	-	73.2	40.2	-	62.0	34.2
Khorasan Razavi	5732687	11	109.2	83.2	144.4	102.5	78.3	123.3
Khorasan South	558038	-	-	68.0	54.2	-	66.6	54.5
Khozestan	4244022	12	79.0	67.0	81.3	66.9	67.7	82.4
Kohkilouyeh B.	631625	4	105.0	70.4	88.2	63.2	39.5	64.2
Kordestan	1441803	19	90.4	106.0	114.5	93.2	73.0	81.9
Lorestan	1696991	19	89.4	73.8	86.8	68.3	67.2	68.6
Markazi	1353771	16	72.0	80.4	87.5	50.9	65.8	79.2
Mazandaran	2898742	35	105.5	107.0	112.9	77.3	88.5	104.6
Qom	1042359	16	94.4	75.3	92.6	66.7	67.7	74.8
Semnan	588180	3	83.4	71.3	106.9	70.0	85.3	91.0
Sistan B.	2396704	11	18.9	29.8	32.8	22.2	25.0	30.5
Tehran	13328011	212	71.0	93.0	106.2	77.0	93.0	102.3
West azarbayjan	2848435	37	117.1	118.0	111.4	84.5	83.0	83.8
Yazd	988443	15	108.1	105.9	113.1	100.2	110.5	113.1
Zanjan	956384	11	83.3	93.9	94.2	58.5	62.6	68.9
Total (IRAN)	**70166948**	**12**	**95.4**	**108.1**	**117.3**	**83.4**	**96.2**	**102.4**

Table 2. ASR of common cancer types among Iranian male in selected provinces which had both pathology-based and population-based cancer registration. 2004 to 2006.

Provinces	Type of Canzcer Registry	ASR All cancers	Stomach	bladder	Prostate	Colorectal	Esophagus	Lung
Ardabil	Population-based	100.3	31.3	8.4	2.8	6.1	11.7	3.4
	Pathology-based	183.7	50.5	10.4	4.6	8.8	17.5	9.4
Kerman	Population-based	84.2	14.6	6.2	5.3	7.3	11.0	2.3
	Pathology-based	183.1	32.0	10.3	11.7	15.9	22.8	17.6
Golestan	Population-based	90.1	9.9	9.0	10.8	8.8	2.8	3.1
	Pathology-based	163.0	19.7	13.2	15.5	10.7	6.8	15.2
Tehran	Population-based	87.2	16.5	11.5	7.8	7.0	6.1	1.5
	Pathology-based	153.0	36.9	7.2	10.1	11.4	11.7	9.2
Semnam	Population-based	77.5	8.2	8.9	3.2	3.8	1.4	4.8
	Pathology-based	76.0	10.3	6.7	3.2	5.9	3.0	7.3
Iran*	Population-based	87.9	16.1	8.8	5.98	6.6	6.6	3.02
	Pathology-based	151.8	29.9	9.6	9.0	10.5	12.4	11.7
Iran	**Path./Pap. Ratio****	**0.58**	**0.54**	**0.92**	**0.66**	**0.63**	**0.53**	**0.26**

* ASRs for Iran is the average of the population-based ASRs reported from each provinces.
** Pathology-based to population-based ASR ratio indicating the under-registration by pathology-based registry

Table 3. ASR of common cancer types among Iranian female in selected provinces which had both pathology-based and population-based cancer registration. 2004 to 2006

Provinces	Type of Canzcer Registry	ASR All cancers	Breast	Colorectal	Stomach	Esophagus	Thyroid	Ovary
Ardabil	Population-based	80.1	8.4	5.6	15.9	15.3	1.9	2.0
	Pathology-based	133.2	11.9	7.4	24.9	19.7	3.3	3.9
Kerman	Population-based	72.6	15.1	5.1	3.9	2.1	3.2	2.5
	Pathology-based	68	16.9	5.9	5.1	1.8	2.4	0.8
Golestan	Population-based	73.9	16.0	5.5	6.2	9.7	2.6	2.6
	Pathology-based	139.8	26.2	9.2	13.1	19.9	3.0	5.8
Tehran	Population-based	90.4	26.5	9.7	5.4	2.5	3.3	3.7
	Pathology-based	142	31.5	9.6	10.0	5.3	2.8	6.5
Semnam	Population-based	82.1	18.0	8.1	5.2	10	2.6	1.9
	Pathology-based	136	21.3	10.5	14.8	8.8	4.5	1.7
Iran*	Population-based	79.8	16.8	6.8	7.3	7.9	2.7	2.5
	Pathology-based	123.8	21.6	8.5	13.6	11.1	3.2	3.7
Iran	**ASR Ratio***	**0.64**	0.78	0.80	0.54	0.71	0.84	0.68

*ASRs for Iran is the average of the population-based ASRs reported from each provinces
** Pathology-based to population-based ASR ratio indicating the under-registration by pathology-based registry

Discussion

We studied the quality of pathology-based cancer registry in Iran. We found that incidence rate of all cancer types combined increased from 2004 to 2006 in overall. However, detailed analyses by province showed that in some regions incidence rate did not increased or even decreased over time. We further found that national pathology-based cancer registry covers only 60-70 percent of the cancer cases. We found a lower coverage for lung, stomach, and esophageal cancers among male and ovary and stomach cancer among female. However, ASRs of colorectal, breast and thyroid cancers among female were almost completely in the pathology-based cancer registry.

This study provided important information concerning quality of cancer registration activities in Iran. Detailed analyses by calendar year, provinces and cancer types revealed hidden caveats in the completeness of the pathology-based cancer registry. Inconstancies in the ASRs over time indicate difficulties in the management of registration system in large country like Iran. We, thus, believe that instead of the national coverage, it might be more reasonable to restrict the registration to a few regions, but follow recommended registration standards and pay particular attention to the quality elements of the registry, including validity, comparability, completeness and timelines .[5, 8]

Main limitation of this study is that only Golestan population-based cancer registry provided annual report for three consecutive years (2004-2007). The rest of data that obtained from Ardabil, Kerman, Semnan, and Tehran registries, reported the cancer incidence rate based on retrospective population-based surveys for a specific time period. However, with the reservation voiced, we believe that this study provide a reasonable measure for underestimation of the pathology-based cancer registry. In a validation study, Farahmand et al showed that in Fars province pathology-based cancer registries register only 60 percent of the cases occurring in the region.[13]

There were large differences on the coverage of pathology-based registry by cancer type. Cancers that are diagnosed in the advance stage and exhibit high fatality rate including lung, esophageal and gastric cancers showed the lowest completeness in the pathology-based registry. Metastatic cancers are usually diagnosed clinically without histological confirmation. On the other hand, ASRs of cancer with relatively good prognosis including thyroid and breast cancers among female and bladder cancer among male were closed to the rates reported by the population-based registries.

In conclusion, this study provided empirical evidence on the limitations and pitfalls of pathology-based cancer registries in Iran. We advocate a quick move from pathology-base to the population-based cancer registry in Iran. It is important to start simply in a limited and defined population and try to secure standards of population-based cancer registry including high validity and completeness. The best practice can be, gradually, extended to other regions, with a particular attention to the information technology. It is also important define the cancer registry as a sustainable program in the health care system.

References

1. Parkin DM, Bray F, Ferlay J, Pisani P. Global cancer statistics, 2002. CA Cancer J Clin. 2005 Mar-Apr;55(2):74-108.

2. Naghavi, Jafari N. Pattern of Mortality in 29 provinces of Islamic Republic of Iran year for year 2005 (in Farsi). Tehran: Iranina Ministry of Medical Education2008.

3.Curado MP, Voti L, Sortino-Rachou AM. Cancer registration data and quality indicators in low and middle income countries: their interpretation and potential use for the improvement of cancer care. Cancer Causes Control. 2009 Jul;20(5):751-6.

4. Valsecchi MG, Steliarova-Foucher E. Cancer registration in developing countries: luxury or necessity? Lancet Oncol. 2008 Feb;9(2):159-67.

5. Parkin DM, Bray F. Evaluation of data quality in the cancer registry: principles and methods Part II. Completeness. Eur J Cancer. 2009 Mar;45(5):756-64.

6. Parkin D, Chen V, Frelay J, J G, Storm H, SL. W. Comparability and Quality Control in Cancer Registration. Lyon: International Agency for Research on Cancer 1994.

7. Jensen O, Parkin DM, Maclenan R, Muir CS, Skeet RG. Cancer Registration: Principles and Methods Lyon: IARC press; 1991.

8. 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 Mar;45(5):747-55.

9. Mousavi S, Guya M, Ramazani R. Cancer Registration Report, for year 2006. Tehran: Cancer Office, Center of Non-communicable Disease Control, Ministry of Health and Medical Education, I.R. of Iran2007.

10. Etemadi A, Sadjadi A, Semnani S, Nouraie SM, Khademi H, Bahadori M. Cancer registry in Iran: a brief overview. Arch Iran Med. 2008 Sep;11(5):577-80.

11. Babaei M, Jaafarzadeh H, Sadjadi AR, Samadi F, Yazdanbod A, Fallah M, et al. Cancer Incidence and Mortality in Ardabil: Report of an Ongoing Population-Based Cancer Registry in Iran, 2004-2006. Iranian J Publ Health. 2009;38(4):35-45.

12. Sadjadi A, Malekzadeh R, Derakhshan MH, Sepehr A, Nouraie M, Sotoudeh M, et al. Cancer occurrence in Ardabil: results of a population-based cancer registry from Iran. Int J Cancer. 2003 Oct 20;107(1):113-8.

13. Nader F, Farahmand M. Prevalence and reporting rate of cancer data from Shiraz hospitalsto Fars Cancer Registry Center. Journal of Isfahan University of Meidcal Sciences. 2008;26(88):14-21.