مقاله تحقیقی

ترویج ثبت سرطان مبتنی بر جمعیت در کشورهای در حال توسعه

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چکیده

اهداف : با توجه به افزایش قابل توجه بروز سرطان درکشورهای توسعه یافته و درحال توسعه، سازمان بهداشت جهانی پیاده سازی برنامه جامع کنترل سرطان را در تمام کشورها توصیه کرده است. در این مطالعه سیر تکاملی ثبت سرطان جمعیتی را که زیربنای اصلی برنامه کنترل سرطان است مورد بررسی قرار دادیم.

روشها: تعداد مناطق ثبت سرطان و میزان پوشش این مناطق را برحسب مناطق مختلف دنیا و کشورهای آنها مورد بررسی قرار دادیم. برای این کار از داده های کتاب *"بروز سرطان در ۵ قاره"* از جلد ۱ تا ۹ استفاده شد. برای محاسبه میزان پوشش ، نسبت جمعیت کشور و منطقه به عنوان وزن هر واحد در نظر گرفته و میانگین وزنی پوشش ثبت سرطان در کشور ها و مناطق مورد مطالعه را تخمین زدیم.

یافته ها : تعداد مناطق تحت پوشش ثبت سرطان در دنیا سیری صعودی داشت. در مجموع ۲۲٤ مرکز ثبت سرطان مبتنی بر جمعیت ۱۹/٦٪ از جمعیت کل دنیا را تحت پوشش ثبت سرطان قرار داده است. در حالی که دربعضی کشورهای غربی پوشش ثبت سرطان تقریبا کامل می باشد، در برخی کشورها بخصوص در آفریقا و آسیا حتی یک مرکز ثبت سرطان هم وجود ندارند. در مجموع پایین ترین میزان پوشش ثبت سرطان در آفریقا (۱/٤٪) و جنوب شرقی آسیا(۲٪) دیده می شود. در کشور آمریکا به دلیل استفاده از فن آوری اطلاعات، پوشش ثبت سرطان رشد قابل توجهی داشته است و میزان پوشش از ۱٤٪ در سال ۱۹۹۷به ۹٦٪ در سال ۲۰۰۲ رسیده است.

نتیجه گیری : کشورهای درحال توسعه باید ایجاد نظام ثبت سرطان جمعیتی را در اولویت قراردهند. الگو گیری از تجربه کشورهای درحال توسعه و موفق ثبت سرطان می تواند تاثیر مهمی در استقرار برنامه مناسب در این کشورها داشته باشد. استفاده از فن آوری اطلاعات پیشرفته فرصت مناسبی برای دست یابی به سیستم ثبت سرطان مبتنی بر جمعیت موثر و مطلوب را فراهم می کند.

کلمات کلیدی : *ثبت سرطان، پوشش، مبتنی بر جمعیت ، کشورهای در حال توسعه*

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ORIGINAL ARTICLE

Fostering Population-Based Cancer Registries in Developing Countries

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A B S T R A C T

Background: Due to the marked increase in the burden of cancer both in the developed and developing countries, World Health Organization recommends planning and implementation of comprehensive cancer control program in all countries. We evaluated evolutionary progress of the population based cancer registries (PBCR), an essential component of the cancer control program.

Methods: We studied frequency and coverage of cancer registries worldwide in overall and stratified by regions and countries, using the data published in the "Cancer in Five Continents (CI5)" volume I-IX. Using the population proportion of the study unit as the weight, we estimated weighted average of the registration coverage in the studied countries and regions.

Results: We found that coverage of cancer registry is increasing worldwide. In overall, 224 PBCRs estimate cancer incidence in 19.6% of world population. While the coverage was almost complete in the western countries, some counties particularly in Africa and Asia lack even a single cancer registry. The lowest coverage was generally observed in Africa (1.4%) and Southeastern Asia (2%). Using information technology, lead to a considerable increase in the coverage of cancer registries in the US, where it increased from 14% percent in 1997 to 96% in 2002.

Conclusion: Developing countries must prioritize establishment of cancer registration system. Looking at the developed countries with well-functioning registries may help establish an efficient registration system in developing countries. Using advance information technology will help achieve an efficient and optimal PBCR.

Keywords: *Cancer, Registry, Coverage, Population Based , International, Developing Country*

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INTRODUCTION

Cancer is the second cause of death worldwide. It has killed 7.6 million (13%) of the world's 58 million deaths in 2005. The cancer incidence estimated to be increased by 45% in developed countries and 75% in the low and middle income countries from the year 2000 through 2025 (1). WHO and other international agencies recommend implementation of a comprehensive cancer control program to mitigate its burden worldwide. Establishment of population based cancer registries (PBCR) will create a promising infrastructure to measure cancer burden at the population level and guide the authorities for an evidence based innervations and policy making to achieve the objectives of the cancer control program(2).

The first population based cancer registry (PBCR) initiated in Denmark in 1942. Since then, several national and international initiatives lead to the evolution of cancer registries worldwide. Standards of cancer registration have been described previously. PBCR collect a set of variables on every case of cancer diagnosed in a defined population. The list of variables abstracted for each case varies based on purpose, feasibility, the resources available for the cancer registry. Minimal variables cover patient's demography including name, place of residence, sex, and tumor information including the topography and morphology of the tumor, date of diagnosis. However, different registries have extended the minimal variable sets and collect more data from cancer cases and their clinical information. Completeness, validity and timeliness are the main criteria to assess the quality of cancer registries (2-4). International Agency for Research on Cancer (IARC) publishes a series of book titled "Cancer Incidence in Five Continents (CI5)" and reports incidence rates from high quality registries worldwide (5).The latest version of CI5 published cancer incidence rates from 65countries. In addition, IARC has developed a data based called GLOBOCAN to estimate cancer incidence for all countries, using the data from CI5 and other international data available from each country(6).

Cancer registries should developed reliable and comparable national and international cancer incidence data in order to achieve their objectives. Table1 presents obligatory data that must be collected in a PBCR. The PBCR need to follow standards for coding, data quality standards, and procedures, recommended by the International Association of Cancer registries (IACR) and the International Agency for Research on Cancer (IARC).Majority of low and middle income countries lack a well-functioning PBCR. Such under reporting of cancer burden from less developed countries could be due to several reasons including poor infrastructure, low priority of cancer control, lack of expert and experienced staff, inadequate funding, etc. (2). Several paper has been published on the validity and quality of cancer registries and has addressed limitations and opportunities in the PBCR (4, 7). However, cancer registration is not prioritized in the low and middle income countries. Given a rich experiments in the field of cancer registry, new registries could build the necessary infrastructure more efficiently and reach the PBCR objectives more efficiently.

We studied evolutionary perceptive of cancer registries to foster establishment of PBCR in the developing countries.

Table 1: Obligatory standards and data in cancer registries

Patient Information	Tumor information
Patients Identification numbers	Tumor incidence date
Name	Most valid base of diagnosis
Birth date	Site of the primary tumor (ICD-O-3)
Age at diagnosis	Histological type (ICD-O-3)
Address (place if residence)	Multiple primary flag

METHODS

We studied frequency of regional/national population-based cancer registries published from volume I to IX of CI5. Information about the number of cancer registries in each country and its coverage was obtained from CI5. We studied population under coverage by cancer registries in Vol. VIII and IX of CI5 in each country. The coverage of the registries published in the book was divided by the total population in the corresponding country to estimate the country coverage. To estimate regional coverage, we estimated weighted average of the coverage, using the population size of the corresponding countries as the weight. Population sizes were obtained from the United Nation Department of Economic and Social Affairs (8). Likewise, we estimated worldwide coverage of cancer registries. We evaluated increasing trends in the number of registries worldwide and stratified by regions, defined based on United Nation classification (5).

RESULTS

Since 1960, number of population based cancer registries published in the CI5 series increased from 30 in volume I to 224 in volume IX (Table2). Cancer registration coverage was different worldwide varying from 100% in the western countries to zero percent in several middle and low income countries (Table 3). Figure 1 illustrates regional variation of cancer registration worldwide in 2002.USA with 43 centers encompassed the largest number of active cancer registry network, while in Argentina, Algeria, Zimbabwe, Pakistan, and Russia cancer incidence rates were reported only from one regional cancer registry. In every new volume of CI5, new cancer registries appear in the book.

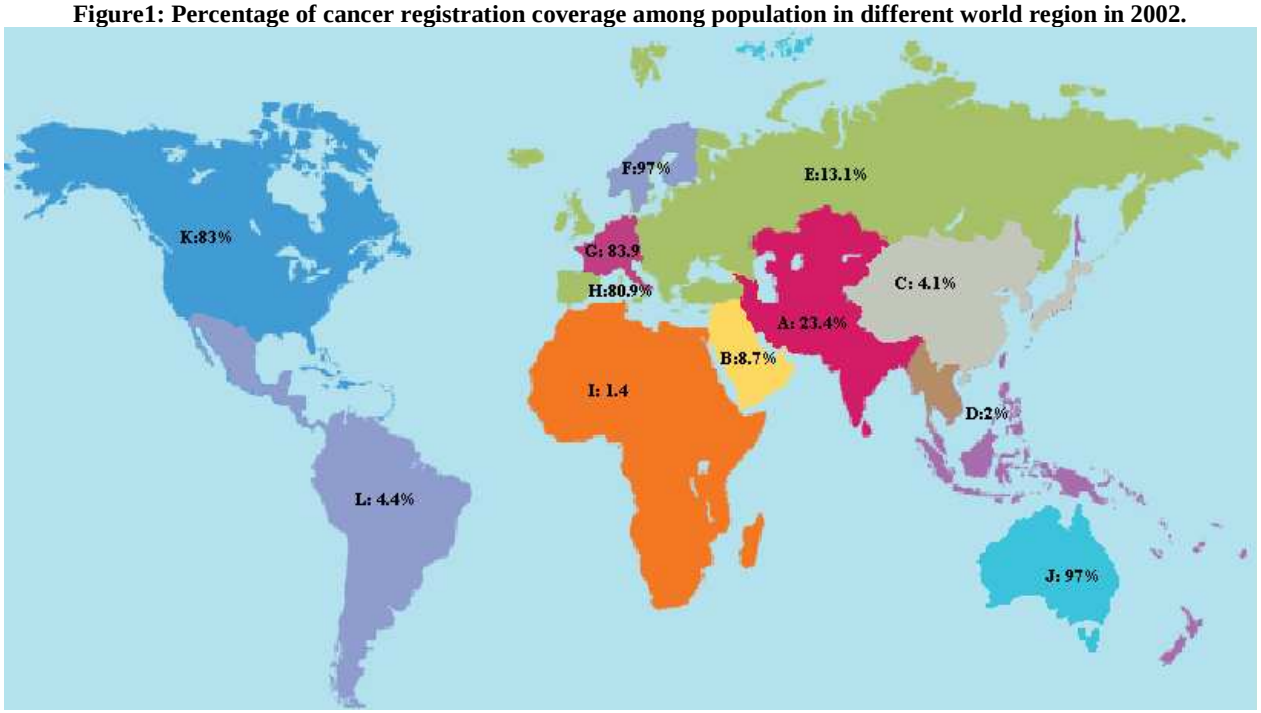
New countries including Bulgaria, Chile, Peru, Serbia, Turkey, Tunisia, and Malaysia showed up for the first time in the volume IX of CI5 (Table 3). In addition, countries who had limited coverage in the previous years, added reports from their new regional cancer registries in Volume IX of CI5. The most rapid increase in the regional cancer registries was observed in USA (form 14 in VIII to 44 in volume IX) and Germany (from one in VIII to seven in IX). In overall during the last 50 years, number of cancer registry reports increased from 30 in 1960 to 224 in 2002. On the other hand, a few countries including Viet Nam, Yugoslavia, Cuba, Uruguay, Mali, Gambia, Cyprus, and Bahrain published their reports in the volume of CI5, but could not sustain and disappeared in the latest reports.

We found that, in overall, 19.6% of 6,109,5000,000 people living in the world in 2002 were covered by the PBCRs. Coverage was higher in Australia and New Zealand (97%), North, (97%), Western (84%) and Southern (81%)Europe, and US and Canada (83%). The lowest coverage was observed in Africa (1.4%), Southeastern (2%), Eastern (4.1%), and Western (8.7%) Asia (Table 3).

Table2: Trends in the number of population based cancer registries published in the IARC Monograph Cancer in Five Continents (CI5)From 960 to 2002

Region	Frequency of cancer registry reports published in different volume of CI5								
	Volum I 1960-1962	Volume II 1963-1967	Volum III 1968-1972	Volum IV 1973-1977	Volume V 1978-1982	Volume VI 1983-1987	Volume VII 1988-1992	Volume VIII 1993-1997	Volume IX 1998-2002
Africa	4	5	3	1	0	3	5	5	5
South-Eastern Asia	1	0	3	3	3	5	6	10	8
South central Asia	0	1	1	2	5	5	6	10	8
Western Asia	1	1	1	1	3	3	3	4	8
Eastern Asia	1	2	3	6	7	10	11	20	21
Eastern Europe	0	8	9	10	7	13	7	8	8
Northern Europe	9	10	13	15	20	23	20	21	20
Western Europe	2	2	4	8	13	17	22	27	33
Southern Europe	1	1	3	4	6	17	26	32	39
Austrailia&Newzeland	1	1	1	3	8	7	7	9	9
South-central America	3	2	5	4	6	8	10	9	10
North Aemrica and Canada	7	10	16	21	25	26	27	27	55
World	**30**	**43**	**62**	**78**	**103**	**137**	**150**	**182**	**224**

Figure1: Percentage of cancer registration coverage among population in different world region in 2002.



A: South- Central Asia
E: Eastern Europe
I: Africa
F: Northern Europe
B: Western Asia
J: Australia & New Zealand
C: Eastern Asia
G: Western Europe
K: North America and Canada
D: South- Eastern Asia
H: Southern Europe
L: South Central America

Table3: Trend of the establishment of Cancer Registration worldwide and the coverage of cancer registries stratified by region and countries based on the published reports in the Volume IIIV and IX of the " Cancer In Five Continents CI5"

Region/country	Population	Volume VIII (1997)		Volume IX (2002)	
		No. of PBCR	Coverage (%)	No. of PBCR	Coverage (%)
Eastern Europe	**304500000**	**8**	**11,4**	**8**	**13,1**
Poland	38140000	4	17	3	9,7
Czech republic	10424926	1	100	1	98,4
Russia	143221000	1	3	1	3,3
Slovak Republic	5400679	1	100	1	100
Bulgaria	7739000	0	0	1	100
Belarus	10179121	1	80	1	80
Northern Europe	**94100000**	**21**	**91,2**	**20**	**97,0**
Sweden	9078000	1	100	1	97,8
UK	60512000	12	83	11	92,4
Norway	4640219	1	100	1	100
Lithuania	3483972	1	100	1	100
Latvia	2292000	1	100	1	100
Ireland	3917203	1	100	1	100
Iceland	300000	1	100	1	100
Finland	5181000	1	100	1	100
Estonia	1400000	1	100	1	100
Denmark	5340000	1	100	1	100
Southern Europe	**145800000**	**32**	**86,1**	**39**	**80,9**
Italy	58779000	16	23	22	29,4
Spain	43060000	11	22	11	22
Yugoslavia	11000000	1	20	0	0
Serbia	5484920	0	0	1	100
Slovenia	1964036	1	100	1	100
Portugal	10547000	1	35	2	73
Malta	404039	1	100	1	100
Croatia	4443000	1	100	1	100
Western Europe	**183500000**	**27**	**75,3**	**33**	**83,9**
Netherlands	16440113	3	100	3	97,3
France	65073482	10	13	11	13,8
Germany	82641000	1	1	7	20,1
Switzerland	7441000	9	40	7	34
Belgium	10415000	2	60	2	60
Austria	8300000	2	10	3	12,8
USA& Canada	**355000000**	**27**	**50,5**	**55**	**83**
USA	308699000	14	14	44	96
Canada	32577000	13	87	11	71,7
Austrailia & New Zealand	**31000000**	**9**	**92**	**9**	**97**
New Zealand	4111000	1	100	1	100
Australia	20530000	8	84	8	93,5

Region/country	Population	Volume VIII (1997)		Volume IX (2002)	
		No. of PBCR	Coverage (%)	No. of PBCR	Coverage (%)
South-central America	**520200000**	**9**	**2,2**	**10**	**4,4**
Argentina	4048200	2	2	1	0,7
Brazil	189323000	2	1	4	7,5
Ecuador	13063000	1	16	1	16
Peru	27836000	0	0	1	1,8
Uruguay	3325000	1	30	0	0
Colombia	43049000	1	4	1	4
Chile	16297000	0	0	1	2
Costa Rica	4328000	1	90	1	90
Cuba	11423952	1	7	0	0
South-EasternAsia	**520400000**	**10**	**2,2**	**8**	**2,0**
Viet Nam	84074000	2	2	0	0
Thailand	65946000	5	10	3	6
Singapore	4267000	3	70	3	70
Malaysia	25633000	0	0	2	14
EasternAsia	**1481100000**	**20**	**5,8**	**21**	**4,1**
China	1330044605	10	4	6	1,4
Japan	127953000	6	12	7	13,2
Korea	48000000	4	35	8	50
South-central Asia	**1486000000**	**10**	**26,5**	**8**	**23,4**
India	1151751000	9	34	7	30
Pakistan	172800000	1	1	1	1,1
Western Asia	**192200000**	**4**	**5,7**	**8**	**8,7**
Kuwait	3399637	2	59	2	78,2
Turkey	71169000	0	0	2	6
Oman	2618000	1	100	1	100
Israel	7000000	1	90	1	90
Cyprus	836000	0	0	1	85
Bahrain	728000	0	0	1	22
Africa	**795700000**	**5**	**0,9**	**5**	**1,4**
Zimbabwe	13349000	1	11	1	13,2
Uganda	33796000	1	4	1	4
Tunisia	10374000	0	0	1	18,3
Algeria	33769669	1	6	1	4,1
Egypt	84474000	0	0	1	5,7
Mali	13323000	1	12	0	0
Gambia	1751000	1	20	0	0
All world	**6,109,500,000**	**182**	**18.2**	**224**	**19.6**

DISCUSSION

In this study we showed that the number and coverage of the population based cancer registries is gradually increasing worldwide, albeit with a regional variation in the increasing trends. Based on volume IX of CI5, only 19.6% of the world population is covered by the cancer registries. The most rapid increase in the number and coverage of cancer registries was observed in the United States and Europe. In the US, several European countries and Australia, almost all population was covered by the registries, while several countries in Africa, South-central America, and Asia had no or limited coverage. Some countries could not sustain validly and completeness of their cancer registries over time and were excluded in the Volume IX of CI5.

Population based cancer registries help public health professionals understand and address the nation's cancer burden. In addition, PBCR helps policy makers and authorities to monitor cancer trends over time, determine cancer patterns in various populations, guide planning and evaluation of cancer control programs (i.e., determine whether prevention, screening, and treatment efforts are making a difference),set priorities for allocating health resources. It also provides valuable infrastructure for advance clinical, epidemiologic, and health services research. While majority of cancers occur in the low and middle income countries, establishment of cancer registries in these regions is ignored. Only three countries from Africa could, so far, published their incidence rates in the CI5. Majority of countries in the Asia that host most of the world population lack well established and standard PBCR.

The most rapid expansion of the cancer registry coverage was observed in US and Germany, and a few European countries. In the US, burden of cancer in the United States was previously estimated only by the data provided by National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. However, the Centers for Disease Control's (CDC) National Program of Cancer Registries (NPCR) provided funds and technical assistance to improve cancer registration throughout the United States. The CDC has administered a national program for cancer registries (NPCR), supporting central registries and promoting the use of registry data in 45 states, the District of Columbia, and the territories of Puerto Rico, the Republic of Palau, and the Virgin Islands (9). With the integration of SEER and NPCR, number of regional cancer registry increased from 14 in volume VIII to 44 in volume IX of CI5 in the USA. At the same time the coverage increased from 14% to 96% (9). Such huge expansion in the coverage was supported by advances in the information technology available in the new century. We believe that US experience will lead to a new paradigm in the establishment of cancer registries and optimizing the PBCR coverage worldwide.

Based on empirical evidence we showed that, it is wise to start and pilot the registration activities in a local area and expand the coverage to the other areas in the country. Initially, scientific and financial support should focus on building a well-functioning registration system to establish reliable and well-functioning population based cancer registration center in the pilot area. Upon achieving the main objective of the cancer registry and providing reliable data, it would be possible to plan for the extension of the system to other area and gradually meet the national coverage. Information technology should play crucial role in the establishment of the new cancer registries. Computers and registration software have been used in most cancer registries to keep, back up and analyses of the data. However, the registration procedures are managed more efficiently with the use of advanced information technology (IT). IT plays important role in the planning, development, management and delivery of cancer registration system. Among the others, in the automated cancer registry, IT plays crucial role in the fostering links with other health agencies, development of interfaces between the PBCR and hospital information systems, development and implementation of formal methods of quality control, development and maintenance of communication protocols between the registry and other data sources, staff training, and documentation, dissemination of the results etc.

Several countries like Iran tried to establish cancer registration to measure the incidence rate of cancer in the country. However, validity and completeness was not reached to a reasonable level to justify publication in the CI5. In the case of Iran, Cancer Office at the Center of Disease Control (CDC), Ministry of Health and Medical Education has established national pathology-based cancer registry to estimate the burden and incidence rate of different cancer types in the country(10, 11). However, it was shown that this registry could only register about 60% percent of the cases and the underestimation pertained to the lung, stomach cancer that are usually diagnosed in the advance stages (12). Such an under reporting in a few cancers will lead to biased and misleading estimates of the cancer burden in the population level. High quality Population based cancer registries involve different standards including timeliness, validity, and completeness that need to be emphasized in each registry (3, 4).

We conclude that majority of developing countries lack well-functioning population based cancer registries. Establishment of PBCRs is crucial to measure burden of cancer, plan and monitor interventions and health policies and implement cancer control program. Instead of making the wheel from the scratch, we suggest using best practices available worldwide and collaborate with counties that exhibit high quality and well-functioning cancer registration system. It will help developing countries bypass most difficulties and achieve an optimal PBCR efficiently, especially in the era of advance technology information system.

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