

COMMENTARY

Challenges to Promoting Population-Based Cancer Registration in Iran: a Workshop Report

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Abstract

In December 2011, the Cancer Research Centre of the Cancer Institute of Iran sponsored a 3-day workshop on “Cancer Registration Principle and Challenges in Iran”, which convened cancer registry experts. The objectives of the workshop were: to introduce standard cancer registration, to review the policy and procedure of cancer registration in Iran, and to review the best practices in the cancer registries in Iran. Challenges to cancer registration were discussed and recommendations were developed. The workshop was evaluated by participants for better organization of subsequent workshops. The objective of publication of this report is that based on Cancer in 5 Continents, many low- or middle-income countries do not meet the criteria for a standard population-based cancer registry (PBCR); on the other hand cancer is the most important cause of mortality and the essential part of any cancer control program is the cancer registry. Therefore this report focuses on problems and challenges of PBCR and provides recommendations which might help other developing countries to decrease their PBCR defects.

Keywords: Workshop report - population - based cancer registry - challenges - Iran

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Introduction

According to the International Agency for Research on Cancer (IARC), 12.7 million people were diagnosed with cancer and 7.6 million died from cancer worldwide in 2008 (Ferlay et al., 2010). Cancer registries are fundamental components of the infrastructure for cancer control programs and data collection and analysis.

A Cancer Registration system includes systematic collection, storage, analysis, interpretation and reporting of cancer-related data. The two main types of cancer registry are the hospital-based and population-based cancer registries (PBCRs). Hospital-based cancer registries are concerned with recording cancer patient's information in a particular hospital, while PBCRs collect data on all new cases of cancer identified in a well-defined population. In many countries, especially high-income countries, PBCRs have been established for a long time and play a critical role in the determination of cancer incidence and mortality. PBCRs thus allow for the measurement of a population's cancer burden and provide critical information for the planning and monitoring of cancer control programs (Silva, 1999). Although more than half of new cancer cases occur in low- or middle-income countries, many such countries lack a well-functioning cancer registry (Parkin,

2006), and this needs to be prioritized. Zendehtdel et.al showed trends in the number of PBCR in the world from 1960-2002 (Keshtmand, 2011) (Table1). According to this table PBCR in Europe and USA increasingly established in four decades but in Africa and Asia this growth trend was not visible. Although in high-income countries the coverage of PBCR is almost 100% but in low- or middle-income countries this coverage hardly is 30%, on the other hand PBCR coverage in Africa is 1.4%, in western Asia 8.7%, in South-central Asia 23.4%, in Eastern Asia 4.1%, in South-eastern Asia 2% and in South-central America 4.4% (Keshtmand, 2011). Several obstacles have been proposed to impede the development of cancer registries in low- or middle-income countries including: a shortage of basic health services and trained personnel, a lack of follow-up, limited census data, a lack of data-processing facilities, lack of population stability, poor individual identification, and a lack of confidentiality (Silva, 1999).

The first cancer registry in Iran began reporting in 1960. In 1969, reports showed a high incidence of esophageal cancer in northern Iran. After this report, the first cancer registry was established in Mazandaran province in northern Iran. The Caspian littoral area that Mazandaran is a part of, has a high incidence of esophageal cancer and is part of the infamous Asian esophageal

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Table 1. Trends in the Number of Population Based Cancer Registries Published in the IARC Monograph Cancer in Five Continents (CI5) From 1960 to 2002 [with the Permission of Basic and Clinical Cancer Research Journal (BCCR)]

Region	Frequency of cancer registry reports published in different volume of CI5 (Volume)								
	Volume I	Volume II	Volume III	Volume IV	Volume V	Volume VI	Volume VII	Volume VIII	Volume IX
	1960-1962	1963-1967	1968-1972	1973-1977	1978-1982	1983-1987	1988-1992	1993-1997	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
Australia and 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

cancer belt (Mohagheghi and Mosavi-Jarrahi, 2010). The Mazandaran registry was a result of collaboration with the IARC. The most sophisticated PBCR in Iran was established by the Cancer Institute of Iran in 1993 to register new cancer cases in the Teheran metropolitan area (Mohagheghi and Mosavi-Jarrahi, 2010). Other PBCRs were established in Ardabil and Golestan Provinces (Mohagheghi and Mosavi-Jarrahi, 2010). At present, most provinces have implemented a pathology-based registry system under the supervision of the Ministry of Health, and some provinces have recently established PBCRs (Mohagheghi and Mosavi-Jarrahi, 2010). However, none of the PBCRs meet standard criteria, and their data have not been included in the Cancer Incidence in Five Continents database (Zendejdel et al., 2011). As a result, the Cancer Research Centre of Cancer Institute of Iran ran a workshop where it reviewed different aspects of standard cancer registration. In addition, during the workshop, different activities of cancer registration in Iran were evaluated and recommendations for improvement were discussed. In this paper, we report the details of this workshop and discuss the recommendations that were made. We also thought this workshop can help other developing countries especially West Asian countries due to similar problems in establishing standard PBCR.

Objectives of the Workshop

The purpose of the workshop was to bring together various stakeholders and interested researchers to: *i)* Introduce standard cancer registry system based on international standards; *ii)* Review the policy and procedure of cancer registry in Iran; *iii)* Identify the strengths and weaknesses of cancer registry in Iran; *iv)* Review the best practices in the cancer registration activities in Iran; and *v)* Discuss strategies for improving PBCR in the country.

The workshop was held from 20-22, December 2011 at Cancer Research Centre of Cancer Institute. The content of the workshop was designed based on IARC summer school on cancer registration, Cancer Registration

Table 2. ASR of Most Common Cancer in Iranian Female in 2008

Cancer type	Golobocan 2008			National Cancer Registry Iran		
	ASR	Frequency (%)	No.	ASR*	Frequency (%)	No.
Breast	18.4	26	5692	33.21	24.86	8424
Colorectal	6.4	7	1822	11.12	7.85	2658
Stomach	9	9.5	2453	10	6.95	2353
Esophagus	6.3	6.4	1661	7.77	5.26	1782
Thyroid	2.3	3	779	4.47	3.88	1314
Leukemia	4	5	1293	6.29	5	1693
Ovary	3.1	3.8	972	4.25	3.23	1096
Brain	2.1	2.6	685	3.09	2.64	894
Uterus	1.7	1.8	466	3.9	2.68	907

Principals and Methods book (Jensen et al., 1991) and presentation of the cancer registration activities in the country. The workshop was followed by an expert panel in which the panelists discussed the challenges and suggested improvement strategies for cancer registration in Iran.

Participants

Thirty five participants including: pathologists (n=7), medical record experts (n=4), medical oncologists (n=2), general practitioners (n=2), epidemiologists and public health professionals (n=20) participated in the workshop.

Day One

Introduction and importance of cancer registration

In the first session, cancer registration and its role in the cancer control program was discussed. In addition, role of international organizations on the promotion of cancer registries and their standards were explained. In overall, 12.7 million new cancer cases and 7.6 million cancer deaths were reported in 2008 worldwide. From these cases, 56% of the cancers and 63% of the deaths occurred in low- and middle-income countries. The most commonly diagnosed cancers in the world were lung, breast, and colorectal cancers; and the most prevalent

cancer deaths were lung, stomach, and liver cancers. It was predicted that cancer incidence in the world would be 21.4 million in 2030, indicating that the number of new cases would increase up to 69%. During this period, the increase in cancer incidence will be 35% in the high-income and 80% in low- and middle-income countries.

In addition to the role of cancer registry system in the monitoring and evaluation of cancer registration program and its action plans, it provides data for different epidemiological studies including descriptive, analytical, clinical, occupational, survival analysis and interventional projects.

The first PBCR was implemented in 1929 in Germany. This type of cancer registration is a process of systematic and continues data collection of reportable cases. PBCR includes every new cases of cancer in defined population in a given time. The general goal in PBCR is the process of evaluation and control of cancer effect on population and it is an essential part of any cancer control program. Data from cancer registry had been used in widespread areas of cancer control such as primary and secondary prevention, etiological research, evaluation of patient care, and health care planning. Overall, the goal of cancer registration is collecting and classifying, creating a linkage between information resources, evaluation of quality of data, and data analysis.

Introduction of international organizations and databases

We devoted a session of the workshop to introduce international organizations and databases including: IARC, IACR, Globocan, SEER program, NAACCR, and European cancer registration network.

The International Association of Cancer Registries (IACR), a subset of World Health Organization (WHO), attempt to support cancer registries worldwide and suggests standard approaches to estimate incidence and mortality of cancer. IARC publishes the book titled *Cancer in Five Continents*. The book could be assumed as a peer review journal that publishes the data and reports of the standard cancer registries submitted to the IARC every four year. The procedure to accept or reject the applications could be assumed as an external evaluation. We should appreciate it and make the publication of results of our registries in this book as the main target and success indicator (Cancer).

IACR is a non-governmental organization and a professional association founded in 1966 to promote PBCR and related activities worldwide. The IACR facilitates the networking and trade of information between cancer registries all over the world to improve data quality (IACR). Globocan is a project in IARC which provides contemporary estimates of the incidence, mortality and prevalence from major type of cancers, at national level, for 184 countries of the world (Ferlay et al., 2010).

Surveillance, Epidemiology and End Results (SEER) program is cancer statistics data base in the United States. This program produces information about incidence, prevalence and survival of cancer in 28% of US population and cancer mortality of all countries (Institute).

The North American Association of Central Cancer

Registries (NAACCR) is a cancer registry organization responsible for producing standard data, holding training course, evaluating PBCR and reporting cancer statistics (Registries).

The European Network of Cancer Registries (ENCR) is another cancer registry organization which acts as a network between cancer registries in European countries (Registries). This organization produces standard data, trains cancer registry personnel, and publishes cancer statistics in Europe.

In Iran, all country covered by pathology-based cancer registry which is under supervision of Ministry of Health and most PBCRs were performed by research centers. Relying to evidences, pathology-based cancer registry data gathered by Ministry of Health is underestimated and it could not be replaced with PBCR (Zendehdel et al., 2011). Data from Ministry of Health in compare with Globocan 2008 showed inconsistency in Age Standardized Incidence Rate (ASR) of some cancers (Cancer, Center for Disease Control and Prevention, 2008-2009) (Table2). However, recently the Ministry of Health launched PBCR registries and we should wait to see the high quality cancer registry from this initiative. We suggest application of standard approaches for the design and implementation of PBCR. Cooperation between research centers and Ministry of Health may strengthen this program. We should pilot all standards of the PBCR in a few provinces and apply the lessons learned from these provinces to extend the program to other regions.

Other challenges were lack of trained cancer registry personnel, poor supervision, and weak cooperation between cancer registries mitigate the success of cancer registration program in Iran. Establishment of cancer registry training program, training of certified registrars, and providing continuous education for the pathologists may enhance the implementation of PBCR in the country.

Day Two

Information technology and cancer registration

Nowadays information technology (IT) has become one of the important and necessary infrastructures in health. IT is the use of modern technology to aid the capture, storage, retrieval, analysis, and communication of information and it plays a crucial role in cancer registration. IT applications in cancer registration includes, but is not limited to: automated case alerts, data collection, better abstraction, quality checking-software, validation system, record linkage, analysis, e-Reporting, Management Information System (MIS), clinical trials information system, networking and collaboration. Challenges in cancer registration and information technology are privacy and confidentiality, data security, inadequate human resources, untrained personnel, no unique ID, minimal use of information technology, difficulty in user training, low quality in medical records, and change in culture. Lack of enough experience and capacity to apply automated approaches in cancer registry is another challenge at the moment in Iran and most low- and middle-income countries. The most important challenge is that how policy makers and stakeholders can use the information

for decision making. We believe that application of IT in the cancer registry system would improve the quality of cancer registry.

Discussion panel for cancer registration in Iran

In the afternoon of the second day, the workshop was continued with a discussion about challenges and opportunities for the cancer registration in Iran. The session commenced with presentation of experiences from three PBCRs including Tehran, Golestan, and Ardabil PBCRs. Panelists were policy makers and experts who were in charge of cancer registries and had sufficient knowledge in the design of surveillance systems and epidemiological research in cancer. All the panel members acknowledged the previous efforts made for the establishment of cancer registries in Iran. However, the standards of cancer registry, validity, and completeness, and timeliness of the PBCRs are not convincing yet. The main conclusions of this session include: *i*) Ongoing national pathology-based cancer registry is appreciated, but PBCRs should be started in different provinces; *ii*) Cooperation of cancer office and research centers should be enhanced with an emphasis on the stewardship of ministry of health and medical education; *iii*) Feasibility and simplicity is a key indicator for a successful and sustainable cancer registry. We need to establish PBCRs in provinces that have more readiness and capacity for the design and management of the system; *iv*) We need to target international standards in the design and management of cancer registry; and *v*) Cancer registry data should be used for the evaluation of cancer control program and epidemiological research.

Day Three

Legal aspects and confidentiality in cancer registry

One of the most important topics in cancer registration is legal aspects and confidentiality issues. Several countries have already introduced legislation on data confidentiality and data protection (Coleman et al., 1992). Reporting of cancer cases to the registries can be compulsory or voluntary (Jensen et al., 1991). There is a growing public awareness of the confidentiality issue and concern over individual privacy.

Although the director of cancer registry is responsible for preserving the confidentiality of data, all the staff of the registry at the time of employment should sign a special contract for the confidentiality and comply with its regulation during their practice (Jensen et al., 1991). The security of electronic data is important and the registries must archive the electronic data in a secure and safe server. Level of access to the data should be defined according to the purpose of the access. At the time of reporting cancer registry data, the principle of confidentiality should be observed. We emphasized that all the users of registry data should be aware of confidentiality issues and must comply with the regulation when using the data for the management and research purposes.

There are no regulation vis-à-vis confidentiality issues in Iranian cancer registries. However, the different levels of confidentiality based on international recommendations have been used. For example based on National Cancer

Registry Guideline, in order to access to data from Cancer Registry, all researchers should have an approval from Ethical Committee. We suggest developing a national standard guideline for confidentiality issues in the cancer registries and emphasize it in the different phase of the registry including data collection, management, data transfer, quality control, analyses, and data sharing.

Cancer registry report

The most important objective of cancer registry is reporting cancer statistics in a well-defined population. The report is part of the health information system in countries and must include three main issues: background information, presentation and evaluation of the results, and tabular section.

Background information must include description of registry, procedures and population coverage.

Evaluations of result include consistency of number of cases in a particular year, site distribution, validity of diagnosis, demographic data, comparing report with similar area to find differences.

Tabular section must contain frequency distribution related to site of cancer, age, and sex. Noted graphical presentation is more attractive than tables. They present trends and comparability of cancer.

Workshop evaluation

We evaluated the workshop based on a questionnaire. In overall, 70% of the participants answered this questionnaire, 81% were satisfied with the workshop and emphasized that workshops like this are needed to increase the knowledge of registration staff and improve the quality of cancer registry in the country. More than 70% suggested more practical sessions during the workshop. About 70% requested more advance workshops for the follow-up.

Conclusion

We found this workshop a useful venue to discuss the challenges and shortcomings of the current registration practice. Network of cancer registries and its personnel may, by themselves, increase their awareness about the standards of cancer registries and, thereby, improve the quality of cancer registries in Iran. Due to a large demand for the training of different aspects of registry and variation of the audiences, different workshops for the training of the registrars and researchers are needed. Periodic workshops on data abstraction, ICD coding, information technology, data analyses, ethics, and confidentiality in cancer registry are needed. Providing a national certification for the registrars and assigning the certified registrars in the cancer registry offices, large hospitals and pathology centers may also strengthen the registration practices in Iran.

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