

## COMMENTARY

# Review of Cancer Registration and Cancer Data in Iran, a Historical Prospect

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### Abstract

Cancer data reporting in Iran dates back to 1960, when the first report of cancer frequency data was prepared and published by the late Prof. Abdollah Habibi, an Iranian pathologist working at the Cancer Institute of Iran. The next data came from two registries, one in the Caspian littoral and the other in Fars province. This paper reviews all activities regarding cancer registry and cancer data in Iran since the early seventies. The authors consider the results published by the different bodies interested in cancer data and make conclusions on prospects for further needs and challenges for cancer registration as a fundamental infrastructure component of a comprehensive cancer control program in Iran.

**Keywords:** Cancer registration data - Iran - history

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### Cancer Registration History in Iran

Cancer data reporting in Iran dates back to 1960, when the first report of cancer frequency data was prepared and published by the late Prof. Abdollah Habibi, an Iranian pathologist working at the Cancer Institute of Iran (Habibi, 1962; 1965). The report included all cancer cases referred to the various pathology departments throughout the country since 1930, a duration of 30 years. This data, for the first time in Iran, was coded using the ICD system, and revealed a high frequency of cancers of the uterine cervix, skin, breast, esophagus, and lymphoma among females and skin, lymphoma, esophagus, larynx, and stomach among males (Habibi, 1970). Although this report was never intended to be a true cancer registry, it has been well appreciated among those epidemiologists in Iran and the region who were interested in tracking changes in cancer frequency (Mosavi-Jarrahi et al., 2001; Etemadi et al., 2008).

As a systematic surveillance, the cancer registry was initially established in 1969, after reports of a high incidence of esophageal cancer in the Caspian littoral of northern Iran (Joint Iran-International Agency for Research on Cancer Study Group, 1977). This registry was launched as a collaborative research agreement between the International Agency for Research on Cancer (IARC) and the Institute for Health Studies affiliated with the Tehran University School of Public Health (Mosavi-Jarrahi et al., 2001; Etemadi et al., 2008). The aim of this registry was to study the high incidence of esophageal cancer in the province of Mazandaran. The published report of this study documented a very high incidence (as

high as 150 cases per 100,000 population) of esophageal cancer among the people living in northern Iran, thereby extending the Asian esophageal cancer belt into the Caspian littoral and middle eastern region of Asia (Kmet and Mahboubi, 1972; Hormozdiari et al., 1975).

The Mazandaran registry provided the basis for several analytical studies addressing the etiology of cancer in the high risk population of the Caspian littoral. Highlighted among these etiological findings was the contribution of the socio-ethnic ingredient of nutritional intake and habits to the high incidence of esophageal cancer in the area (Mahboubi et al., 1973; Hormozdiari et al., 1975; Hashemi et al., 1979). By 1971, this registry expanded its activity to cover the entire Caspian littoral: from the northern part of the province of Khorasan to the northern part of the province of East Azarbaijan. The expansion of the registry, further highlighted the peculiar cancer distribution in the Caspian littoral with a low incidence of upper GI (esophageal and stomach) cancers in the central littoral (the province of Gilan) and very high incidence of upper GI cancers in the eastern and western areas of the littoral, populated by two major ethnicities, Turkmens and Turks, respectively (Saidi et al., 2002; Sadjadi et al., 2003; Mosavi-Jarrahi and Mohagheghi, 2006; Semnani et al., 2005). This registry was able to generate population data for ten years (1968 to 1979) but its activity ceased in early 1980, and was then restarted in early 2000 with new aims and better logistics, enjoying advanced technology.

In 1976, another population-based cancer registry was established in the province of Fars, and expanded its activity to the neighboring provinces of Khuzestan and Bakhtaran (the latter of which is now known as

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Kermanshah) to include vast areas in western Iran (Barekat et al., 1971; Haghghi et al., 1971; Haghghi et al., 1974). The activities of this registry were limited to the registration of histopathologically confirmed cases that had been referred to the pathology departments in the area, or cases from this area that had been referred for treatment at radiotherapy facilities in the city of Shiraz. The early data published by this registry reported high frequencies of skin, stomach, lymphoma, breast, cervix cancers and a low frequency of esophageal cancer among the population living in the central part of Iran populated mainly by ethnic Persians (Barekat et al., 1971). The findings of this registry showed a picture of cancer prevalence different from that of the Caspian littoral. This registry is still publishing cancer frequency data, without reference to a defined population.

## Cancer Registration Program in Iran

In 1993, the Cancer Institute, affiliated with the Tehran University of Medical Sciences and with a grant from the Ministry of Health and Medical Education, initiated a cancer registry program to assist public health authorities in different regions of the country to establish regional population-based cancer registries. This effort resulted in series of activities in different regions, including a collaborative research agreement with the IARC in December of 1999, to establish a population-based cancer registry in the Tehran metropolitan area, currently covering a population of close to 8,000,000 people (Mosavi-Jarrahi et al., 2001). As the most comprehensive cancer registry program in the country, it shares technology and data with the other regional registries in the country.

The population of Iran is composed of Kurd, Lur, Persian, Turk, Baluch and Arab ethnicities scattered in different regions of the country (Sepehr et al., 2004). The Tehran population-based cancer registry covers a population fairly representative of the country's regional and ethnic diversities, who have immigrated to Tehran during the last 50 to 60 years. Although the proportion of each ethnic group in Tehran has not been determined, it appears to be fairly proportional to the total population of each ethnic group in the country.

In response to the emergence of chronic diseases, especially cancer as a major cause of morbidity and mortality, in 1984, a bill was passed by the National House of Representatives that required cancer cases to be reported to the Ministry of Health and Medical Education. However, without a functional system to manage these reports, no morbidity or mortality data were generated until 1999, when the infrastructure to support compulsory reporting was established through an automated electronic system. Since then, cancer cases diagnosed in pathology departments all over the country have been reported to the Office of Cancer and Genetic Diseases, a subdivision of the Center for Disease Control in the Ministry of Health. In the early years of this activity, the passive nature of case reporting brought serious challenges in terms of completeness of reports. This challenge was met with several policy amendments such that, although the first year of this activity was able to register just 18% of cancer

cases, in 2005 this figure was close to 70%.

With the assistance of several university research centers, especially the Digestive Disease Research Center at the Tehran University of Medical Services, in order to address the lack of completeness in passive reporting and investigate the high incidence of gastrointestinal cancer in the country, the Cancer Office at the Ministry of Health established a regional population-based registry in 1992, which covered an ethnically diverse population of 9.5 million living in the provinces of Ardabil (northwestern Iran), Kerman (southeastern the country), Golestan (northeastern Iran), and Semnan (central Iran). The program developed uniform case-ascertainment techniques and included all sources of data including cancer cases reported through death certificates.

This five-province program joined efforts with the Cancer Institute's Tehran population-based cancer registry in order to address the problem of referral cases outside the covered population, which stemmed from the fact that most cancer patients throughout the country seek diagnostic and medical treatment in Tehran either due to lack of proper facilities (such as radiotherapy facilities) or to obtain better-quality treatment and diagnostic services. The establishment of the regional population-based cancer registry, in conjunction with the activities of the Cancer Institute within the Tehran metropolis, has brought a better picture of cancer distribution around the country. The registry in Tehran has reported a world age standard rate of 163 and 142 for males and females, respectively, per 100,000 population (Mohagheghi and Mosavi-Jarrahi, 1998).

## Cancer Prevalence

Cancers of the stomach, prostate, lung and bladder, and lymphoma were found to be most frequent in males and cancers of the breast, stomach and ovary and lymphoma were most frequent among females (Mohagheghi et al., 2009). The other regional registry reported a different picture. For Ardabil, covering a population of primarily Kurd ethnicity, it reported a high incidence of stomach and esophageal cancer among both males and females, with breast cancer third in rank. For Golestan, covering a mixture of Persian, Turkman and migrant Baluch ethnic groups, it reported high incidences of esophageal cancer in males and breast cancer in females. For Kerman and Semnan, covering a population of Persians living in the central part of the country, reported a high incidence of skin, stomach, esophageal cancers as well as lymphoma among males, and skin, breast, ovary and uterine cancers among females. There has been no report of high rates of cervical cancer, as was first reported in the early cancer survey of the 1970s.

Overall, the spectrum of cancer in Iran has recently been dealt with by the establishment of several and diverse means of cancer data collection. Cancer reports from the main and regional cancer registries have already shed much light on the different patterns of cancer occurrence among the various ethnic populations of this country. The high incidence of stomach cancer and increasing incidence of cancers of the colon, prostate, lung, bladder

along with the reduction in the incidence of esophageal cancer are the broad trends nationwide. As the registries age, gain experience and produce reports, the prospect of a collective and integrated cancer control program in the public health arena is more achievable due to the very basic aim of this and any cancer registry program.

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